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ABSTRACT

This final report summarizes the objectives, activities and outcomes of a federally funded program that was designed to provide parent training and early intervention services to children and families in 4 counties of north Alabama. A total of 61 children were enrolled in the project over three years. All were less than 36 months of age and had varying severities of conditions. They came from rural, small town and urban homes, and were from a variety of socio-economic strata. Most children participated in both home visits and group classes. Families received ongoing support and training from staff members, and this was seen by staff members as the strongest aspect of the program. Families' evaluations of the program also reflected general satisfaction with the support and training they received. This report contains overviews of the services provided to children, the services provided to parents, staff development activities, community relations/demonstration/dissemination activities, and program evaluations. (SG)

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ED 468 015

Final Report

MADISON AREA HIGH RISK PROJECT

Grant Number: G008302260

Date of Report: October 21, 1986

Project Directors: Linda Pohuski (1982-84)
Susan J. Smith (1985-86)

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Final Report

MADISON AREA HIGH RISK PROJECT

Grant Number: G008302260

CFDA: 84.024B

Period of Award: October 1, 1983 through September 30, 1986

Project Directors: Linda Pohuski (1982-84)
Susan J. Smith (1985-86)

Grantee: Madison County Association for Retarded Citizens
Huntsville, Alabama
Directors: Elizabeth McMurtrie (1983-84)
Charles F. Everest (1985-86)

Date of Report: October 21, 1986

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The Madison Area High Risk Project (HRP) was established to provide parent training and early intervention services to families in the 13 counties of north Alabama. According to the Program Philosophy and Objectives, children eligible for enrollment in the Project include:

> Infants whose early-appearing, aberrant development is related to diagnosed medical disorders of known etiology with reasonable expectation of developmental delay.
>
> Infants who are at environmental risk, including those who are biologically sound but whose life experiences are limited so that, without corrective intervention, there is a high probability for delayed development. Such life experiences may include maternal and family care, health care, patterns of physical and social stimulation, and opportunities for expression of adaptive behaviors.
>
> Infants who are at biological risk, including those whose history of prenatal, perinatal, neonatal and/or early development suggests biological insult to the developing central nervous system with the increased probability of later-appearing developmental delay.

Children enrolled in the Project were to be less than 36 months of age and have varying severities of conditions. Because of the geographic nature of north Alabama, it was anticipated that children would come from very rural, small town and urban homes and from all socio-economic strata.

PROGRAM OBJECTIVES

The original objectives of the High Risk Project, as stated in the grant proposal, were:

1. to facilitate the intellectual, emotional, physical, mental, social, and language development of infants aged 0-3 years by developing, implementing, and demonstrating an education service program for 30-40 such children in the Madison County area.

2. to encourage the effective and meaningful participation of 30-40 parents in the development of their high risk infant by involving parents in the planning, development, operation, and evaluation of the project, and by training parents to participate in the individual education intervention plan for their child.

3. to provide an effective means of assessing children's progress by establishing, evaluating, and updating every six months Individual Education Plans (IEPs) for each child participating in the project, and by preparing and evaluating activity charts of three to four specific behaviors or tasks to be learned or performed by the child every two weeks.

4. to coordinate the project with public schools and other agencies working with handicapped children by providing specialized resource and training assistance to these organizations at the time a child moves from the High Risk Project to one of their programs, thus facilitating a smooth transition.

5. to establish an advisory council which will assist actively in: a) planning, development and operation of the project; b) acquainting the community with the project; c) disseminating information about the project; and d) evaluating the success of the project by soliciting members from a range of sources including the medical community, local schools, civic organizations, and parents, and by scheduling monthly meetings for the first three months and every two months thereafter.

6. to facilitate widespread understanding and support for early education for handicapped children by disseminating information about the project both locally and beyond, and by producing materials and other package information for demonstration purposes.

Since these objectives were largely unmeasurable, in Year Two the Project staff, with technical assistance from a TADS consultant, revised the Project's objectives to read:

1. to provide an early intervention program in North Albama for 30-40 high risk infants aged 0-36 months with all levels of handicapping conditions.

2. to provide an effective means of assessing children's progress by establishing, evaluating and updating every three to six months Individual Educations Plans (IEPs) for each child participating in the Project.

3. to provide training for parents to assist and support them in teaching their child needed skills.

4. to provide four informative parent meetings a year.

5. to provide a smooth transition for children between the Project and public schools or other agencies by providing resource and training assistance to these organizations.

6. to provide for the continuing professional development of Project staff members through a combination of workshops, conferences and on-site visitations.

7. to disseminate information about the High Risk Project and the needs of young children through the local media and distribution of Project materials to appropriate individuals and agencies.

Each of these objectives is dealt with in this report in the appropriate content section. When necessary an objective may be referred to in more than one section.

SERVICES TO CHILDREN

SERVICES TO CHILDREN

The High Risk Project's Program Philosophy begins with these words:

> The Madison Area High Risk Project was founded in the belief that very young children with developmental delays/disabilities, or at risk of having such a condition, need a concentrated program of early intervention to minimize the negative effects of the delays/disabilities and to facilitate the child's optimum development. Because medical services are not sufficient to promote the maximum intellectual, emotional, physical, social and language development in such children, the High Risk Project provides a multi-disciplinary early intervention program designed to meet the needs of high risk children (ages 0 to 36 months) and their families.
>
> Since the needs of individual children and their families are each unique, the program is sufficiently flexible to respond to these differences. Programming and expectations for each family unit are tailored to the abilities, needs and desires of the child and family.

The program objectives which specifically address services to children are:

1. to provide an early intervention program in North Alabama for 30-40 high risk infants ages 0-36 months with all levels of handicapping conditions;

2. to provide an effective means of assessing children's progress by establishing, evaluating and updating every three to six months Individual Education Plans (IEPs) for each child participating in the Project; and

5. to provide a smooth transition for children between the Project and public schools or other agencies by providing resource and training assistance to these organizations.

ENROLLMENT

According to the High Risk Project's grant proposal, the Project was to serve children in the 13 counties of north Alabama. However, it was determined early in Year One that most children in northwest and north-central Alabama had access to early intervention programs. While these programs were generally center-based rather than home-based, the High Risk Project decided to serve families in Morgan and Limestone Counties (north-central Alabama) only if they were unable to participate in the programs in their county seats. Therefore, the High Risk Project has concentrated on serving children in Madison, Marshall, Jackson and DeKalb counties. The only other programs serving handicapped children in these counties are the state-wide Parent Infant Program for sensory-impaired children, the United Cerebral Palsy centers in Huntsville and Gadsden, and the Huntsville Achievement School (monthly tuition $200+). Like the HRP, the Parent-Infant Program is home-based; the other programs are center-based. The map on page 15 shows the geographic distribution of children who have received HRP services in its first three years.

It did not take a great deal of staff effort to recruit children with a broad range of handicapping conditions and degrees of severity. By working closely with the local perinatal follow-thru clinic, our primary referral source, and with private pediatricians, the HRP received referrals that fulfilled this commitment.

The chart on the following page shows the number of children with each condition served through August, 1986.

ENROLLMENT BY CONDITION OF CHILDREN IN HIGH RISK PROJECT

Condition	Number of Children
Down's syndrome	12
Other chromosome disorder	2
Spina bifida	1
Complications of meningitis	4
Complications of prematurity	22*
Complications of perinatal asphyxia (term births)	6<
Tuberous sclerosis	1
Fetal alcohol syndrome	1
Effects of brain lesion	1
Severe environmental deprivation	2
Developmental delay of unknown etiology	8

* Nine of these children were eventually diagnosed as having cerebral palsy

< Five of these children were eventually diagnosed as having cerebral palsy

In the earliest days of the HRP, the plan was to accept any child who was at risk of developmental delay, but it was quickly realized that all 400+ children cared for in the intensive care nursery at Huntsville Hospital each year were "at risk", along with many other children who never required NICU care. The perinatal follow-thru clinic and the HRP staff, therefore, decided to enroll children only if indications of developmental delay were appearing or if parents obviously needed training and support. Children with conditions such as Down's syndrome automatically qualified for enrollment.

The attempt to maintain a socio-economic balance was affected by the strong relationship between inadequate nutrition and prenatal care on one hand and premature births on the other. A May 1986 survey showed that 32% of the enrolled families had annual incomes below the federal poverty level; an additional 16%

of the families had incomes between 100% and 150% of poverty level.

The racial/ethnic breakdown of enrolled children was:

Caucasian	75%
Black	20%
Hispanic	5%

Considering that the percentage of Black individuals in the total population of the area served is approximately 12% and that 75% of our families with incomes below federal poverty level are Black, Black families participation in the HRP as 20% of our enrollment is again indication of the relationship between economic status and premature births.

During Year One and the early months of Year Two, the HRP served a very small number of children while much of the staff's efforts were directed toward model development. When a project director with model development experience became a staff member and began evaluating and assuming responsibility for some of these tasks, direct-service staff was freed to increase the number of children being served. When the Project's social worker moved out-of-state, the Project director assumed most of her responsibilities so a second developmental specialist could be added to serve more children in Year Three. These changes made the program appear more cost-effective to potential funding sources and proved a substantial need for such a program in northeast Alabama.

The following chart demonstrates the growth in enrollment during the Project's first three years:

March 1984	9 children
September 1984	9
March 1985	14
September 1985	18
March 1986	29
September 1986	34

During this time a total of 61 children were served, with an additional three children assessed but determined to be more appropriate for enrollment in other programs or not truly in need of services. At only one time was it necessary to place a child on a waiting list until her enrollment could be processed. The child's parents were given copies of appropriate pages from *Teaching Activities: Newborn to 36 Months*, written by the Developmental Education Birth through Two Project in Lubbock, Texas.

PROGRAMMING FOR CHILDREN

Over the lifetime of the High Risk Project, the number of programming options offered to parents increased. Initially all of the direct service staff members (full-time developmental specialist, physical therapist and social worker and a half-time nurse) made bi-weekly home visits as a team to most of the children. When the physical therapist and nurse resigned their positions, they were not replaced as such, but in Year Two contracts were signed with local speech and rehabilitation centers to provide speech-language pathologists and occupational therapists to the HRP on an hourly basis. (Henceforth, the terms "speech-language pathologist" and "speech therapist" will be used interchangeably. While not entirely accurate, this enables the use of the term "therapists" to refer to all HRP staff members specifically trained in speech-language or physical development.) The therapists used rooms at the Opportunity Center (office-home of the HRP) in the afternoon and parents who had transportation to the Center brought their children for bi-weekly appointments. Whenever possible, home visits and Center sessions were scheduled on alternate weeks.

Because parents' transportation to the Center was not always available or reliable and the children's illnesses caused frequent cancellations of therapy sessions, toward the end of Year Two the staff was looking for ways to make the therapists' time more cost-effective. The Project staff was also interested in getting parents together more often than during the occasional parent meetings. After discussion with the HRP's TADS consultant and others, and a trip to Houston, Texas, to observe the Mental Health and Mental Retardation Authority of Harris County's program (including group classes), the HRP initiated its own form of group classes in October 1985. Because classroom space at the Opportunity Center was not available in the mornings, arrangements werre made with a local church to hold group classes in a church school classroom there.

By scheduling four or five children to see both speech and occupational therapists during a one-and-a-half hour block of time, the inconveniences of cancellations and "no-shows" is virtually eliminated. The developmental specialists who make home visits to each child attend these therapy sessions to facilitate carry-over of activities into the home. By arranging class make-up so that children with similar developmental levels and/or conditions attend at the same time, parent interaction and sharing are encouraged. While these sessions are quite different from the preschool-type sessions envisioned when the original grant proposal was written, they have proven much more satisfactory considering the very young ages of the children involved.

For those few children whose medical conditions preclude their participation in group classes, individual appointments with the therapists remain available. If a family is unable to bring their child to the therapy session, the therapist acts as a consultant to the developmental specialist, suggesting activities based on the specialist's observations and reports. The original plan to establish satellite locations wherre parents in outlying counties could see the therapists without having to travel to Huntsville did not prove feasible, primarily because of the unavailability of therapists in those locations.

Because the needs of the enrolled children and their families vary greatly, the HRP attempts to provide the maximum amount of flexibility in programming. While most children participate in both home visits and group classes, the lack of transportation or constraints in the parents' schedules preclude some children's attending morning group classes. An afternoon group was begun to include three children who could attend then. Several children who began the HRP using all program components progressed in some developmental areas to the point that they discontinued home visits while continuing group classes.

The expense of paying for travelling time for the therapists prevents the HRP from sending them into the children's home except in the most extreme cases. Volunteer drivers, taxi cabs and other means have been used to help families without transportation get to group classes when necessary and feasible.

The staff of the HRP is firmly convinced that the benefits of visiting in each child's home make the travel and inconvenience well worth the effort. The fact that both parent and child are seen in a comfortable setting enables the developmental specialist to observe their natural style of interaction and to easily assess changes in behavior and skill development. Parents find it easier to understand and implement activity suggestions given in the home, and the developmental specialist can tailor his/her suggestions and expectations to the individual situation. In every evaluation process offered to parents, the overwhelming response was that home visits were the most valuable aspect of the HRP.

The actual content of each type of sessions will be described in the "Services to Parents" section of this report.

ASSESSMENTS AND CURRICULUM

The Hawaii Early Learning Profile (HELP Chart) is the primary assessment tool used by the developmental specialists, the speech-language pathologists and physical and occupational therapists. The Bayley Scales of Infant Development is administered to each child on enrolling and withdrawing from the Project as verification of developmental level shown on the HELP Chart and to compare skill levels when entering and leaving the program.

Through the middle of Year Two the developmental specialist spent a great deal of time creating "activity charts" to leave with parents between home visits. With activities and suggestions similar to the HELP Activity Guide, the charts also required parents to document the number of times each activivity was presented during a two-week period and the results each time. (Sample activity chart is on page 16.) After lengthy discussions with a TADS consultant, the Project director realized that the HRP was not funded or staffed to produce a marketable curriculum and that staff efforts could better be directed toward researching and cross-referencing a number of other established curricula. To this end, the following curricula were obtained and are used by all HRP staff to supplement the HELP Activity Guide when appropriate:

Small Wonder
Comp Curriculum (Pennsylvania State University)
Learning Steps
Preschool Program of Studies (Fairfax County, VA)
The Louisiana Curriculum for Infants with Handicaps
MH/MR Authority of Harris County (TX) curriculum
Developmental Programming for Infants and Young Children
Child Development Resources Curriculum (Lightfoot, VA)
Carolina Curriculum for Handicapped Infants
Education for Multihandicapped Infants
0 to 3 Early Language Curriculum

The activity charts developed by the HRP prior to June 1985 are also used, without the requirement that parents document attempts and accomplishments.

Appropriate items from any of the above curricula can be incorporated into each child's Individual Education Plan (IEP). IEPs are written by the developmental specialist, with input from the parents and the various therapists, as soon as possible after the child enrolls in the HRP and are updated every six months, in February and August. A copy of their child's IEP is always to given to parents at the IEP meeting. A sample of the IEP form is on pages 17 through 20.

COORDINATION WITH OTHER PROGRAMS

For a few of the children in the HRP, concurrent enrollment in another program is appropriate. The Parent Infant Program (PIP) of the Alabama Institute for the Deaf and Blind is an early intervention program for sensory-impaired children. PIP's parent advisors are not usually trained in working with gross and fine motor delays, except to the extent that they are affected by vision. Depending on the child's and family's needs, the HRP and PIP sometimes serve as consultants to one another, but sometimes enrollment in both programs is most appropriate. The Memorandum of Agreement on page 21 defines the relationship between the two programs. A similar sharing has occurred with three children enrolled in United Cerebral Palsy programs whose parents very much needed the continued support and encouragement of home visits, at least for a period of transition.

In most cases, when a child leaves the HRP, he/she either transfers entirely to another program or no longer needs early intervention services. The chart below shows reasons for withdrawal of the 26 children who left the HRP by August 1986.

Post-HRP Placement	Name of Child
Madison County ARC Preschool	Ashley, Damen
Marshall County ARC Preschool	Paula, Chad
Huntsville C. P. Center	Matthew H, Chris
Gadsden C. P. Center	Matthew R
Huntsville Achievement School	Kristen, Suzan

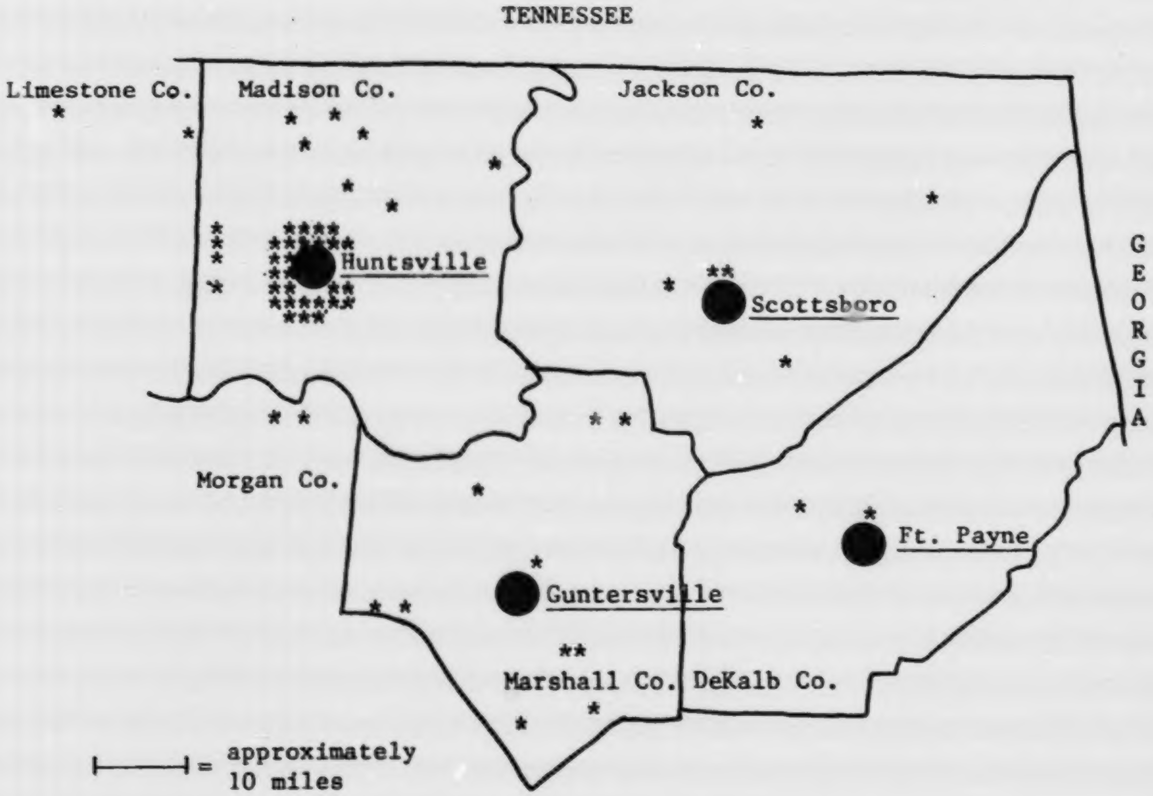
No longer in need of services--Jacque, Rodney, William, Tabbitha
Withdrawn at parent's request--Emma, Kimberly, Justin, Chris
Moved from area--Jarrod, Brian, Patricia, Stephen, Heather
Dropped from enrollment for "no shows"--Vernon, Antwone, Christina
Died--Kasey

Parents of children who are dropped from enrollment because they have had three uncancelled "no shows" are usually contacted at the end of three months and offered re-enrollment. Parents of children who leave the HRP for any other reason are contacted after three months to see how the child and family are doing. If the child left the HRP because his/her skill development had reached an age-appropriate level, a three-month follow-up assessment is always offered to be certain that a normal rate of progress is continuing. Particularly in these cases, if the parent's ability to continue providing appropriate stimulation is questioned, a copy of the suitable pages from Teaching Activities: Newborn to 36 Months will be given to the parent at the time of withdrawal.

Since public schools in northeast Alabama do not generally serve children under kindergarten age, the HRP's contact with local school systems has been minimal. Since Jackson County does not have any pre-kindergarten special education program except for speech therapy, it is anticipated that some Jackson County children will remain in the HRP until they enroll in public schools there.

GEOGRAPHIC DISTRIBUTION OF CHILDREN SERVED BY MADISON AREA HIGH RISK PROJECT

October 1984 -- September 1986


TENNESSEE
Limestone Co.
Madison Co.
Jackson Co.
Huntsville
Scottsboro
GEORGIA
Morgan Co.
Ft. Payne
Guntersville
Marshall Co.
DeKalb Co.
= approximately 10 miles

* indicates location of home of one child

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ACTIVITY CHART

All activities are given as "ideas". Each child is different and will respond to each activity differently. Please feel free to change the activities to better suit you and your child. Also, please write your suggestions down. They may be helpful to others.

Skill Area: Cognitive

Goal: Will increase body awareness

Objective: (4) Play with fngers and hands 3/5 times observed.

Activity: A. Place brightly colored rings on your child's hands to encourage looking at and playing with hands. Snap beads may be used on fingers. Verbally encourage your child and talk about color, shape and size of objects.

Materials: Rings

DATE	NUMBER DONE	DATE	NUMBER DONE

Madison Area
High Risk Project

INDIVIDUAL EDUCATION PLAN

CLIENT NAME: ______________________ CASE # ____________

DATE OF CURRENT IEP STAFFING ______ INITIAL PLAN ☐ REVISED PLAN ☐

START DATE FOR IMPLEMENTING IEP ____________ REVISED DATE ______

ESTIMATED LENGTH OF SERVICE ______________________

LONG TERM GOAL: ______________________

____

Conditions (e.g. Developmental delays, hearing impairment, etc.) ________

____

Medical Alerts: ______________________

SERVICE COMPONENTS PROVIDED:

Individual	Group	Speech	OT	PT	Other

P.O. Box 1063 • Huntsville, Alabama [illegible]5807
A Division of the Madison Co. ARC

INDIVIDUAL EDUCATION PLAN

CLIENT'S NAME: ______________________ CLIENT'S NUMBER: __________

DATE: ______________________________

I. Participants in the Individual Education Plan and Review Meeting

II. Persons providing written input but who did not attend meeting

III. Parent/Guardian Input:

We acknowledge and accept this IEP in its present format. We understand that we are responsible to implement the activities provided in accordance with this IEP.

Parent's Signature ______________________ Date ______________

EVALUATION SUMMARY

NAME:
AREA:
DATE OF REPORT:
DATE OF EVALUATION:

INITIAL:
UPDATE:
SPECIAL:

completed for gross motor, fine motor, cognitive, language, self-help and social areas of development

SIGNATURE

Madison Area
High Risk Project

INDIVIDUAL EDUCATION PLAN

____________________ Name __________ Case #

Long Term Goal: ______________ will improve in
______________ skills in one year.

______________'s parents will be responsible for implementing the objectives of this plan.

OBJECTIVES	Start Date	Target Date	Accomp Date	Activity Sheets
one objective page completed for				
each of six areas of development				

Memorandum of Agreement
Between
Parent Infant Preschool Program (Region 2)
and
Madison Area High Risk Project

The purpose of this document is to establish a cooperative agreement to serve the preschool sensory impaired child in PIP Region 2 between PIP and the High Risk Project.

The Parent Infant Preschool Program identifies and provides home intervention services for the sensory impaired preschool child 0 - 5 years in a 5 county area: Limestone, Madison, Marshall, Jackson and DeKalb. These services are provided by Parent Advisors trained to serve the hearing and/or visually impaired child and his family. In some areas of some of the counties Parent Advisors are not as yet available to serve some children on an active basis. It is proposed that the High Risk Project could serve such a family on an active basis with PIP being a supportive service by providing a Parent Advisor consultant for this family-especially in the areas of the hearing and/or vision problems. Conversely, in instances where a PIP Parent Advisor is serving a multi-handicapped sensory impaired child, the High Risk Developmental Specialist could offer consultant services to the Parent Advisor. This could include activities further assessment, etc.

The High Risk Project serves handicapped and developmentally delayed children 0-3 years of age, primarily in Madison, Marshall and Jackson counties. Services to children 3-5 years old or in other counties of north Alabama can be provided if no other appropriate program is available. Using a team consisting of speech/language, physical and occupational therapists and developmental specialists, the HRP trains parents to maximize the skill development of their children.

It is the intent of this agreement to avoid duplication and/or conflict of services to these children by the following means:

1) Any child served cooperatively will be fully enrolled in each program. The High Risk Specialist or PIP Parent Advisor can serve as consultant to the child's overall program as needed. There will not be duplication of child count since funding for these programs differ.
2) The initial case management will be handled by the agency first receiving referral. Responsibility for coordination of the IEP and determination of the extent of program services needed will be decided on an individual basis.
3) Each agency will submit paperwork as required by their administrative structure. In addition, each agency will share information as needed to serve the child.
4) A primary goal will be to make these cooperative services as simple for the parent and child as possible.
5) The PIP and High Risk Project personnel will be able to share programming ideas, materials and In-service training.

The terms of this agreement will be   to

SERVICES TO PARENTS

SERVICES TO PARENTS

The High Risk Project's program objectives which specifically address services to parents are:

> 3. to provide training for parents to assist and support them in teaching their child needed skills; and
>
> 4. to provide four informative parent meetings each year.

The philosophy statement of the HRP establishes the parent-training focus of the home and center sessions with these words:

> Because parents are the primary models for their children, the effectiveness of the High Risk Project depends on the parents' taking an active role in their child's development. The Project staff's training and support of parents are designed to assist them in developing or strengthening the expectations, attitudes, knowledge and skills they need to enhance their child's development.

Because of this focus, enrollment of a child in the HRP is really enrollment of the parent-and-child. A parent or parent substitute must be present for all sessions. During home visits, the developmental specialist assesses the child's development of new skills, then demonstrates to the parent activities to do with the child to encourage the acquisition of further skills. During group classes, the speech-language pathologist, physical and occupational therapists assess development in their particular area and give parents suggestions of techniques and activities to promote language and physical development. All HRP staff members stress continually to the parents that the children are not seen by professionals frequently enough or long enough to make a significant difference in their development. HRP therapists and specialists can only support and guide the parents to increase the impact they will have on their children's progress. Being parent educators requires of the staff a somewhat different set of skills from those needed in a strictly child-focused program. Developing these skills and permitting parents to absorb information at their individual rates have certainly been the greatest personal/professional challenges encountered by the HRP staff.

PARENT LITERATURE

When parents first contact the HRP for information about enrolling their child, a home visit by the Project director is usually arranged. At this time, the child's and family's needs are discussed, the HRP programs explained, and an informational packet given. Included in this packet are:

(1) an HRP program brochure and fact sheet;

(2) an HRP parents' handbook, describing more fully the program logistics and mutual expectations;

(3) a list of books and articles available for borrowing from the lending library;

(4) a glossary of terms often encountered in early intervention programs;

(5) information about parents' and children's rights under Public Law 94-142;

(6) safety tips for infants and toddlers;

(7) an overview of child development to age 36 months;

(8) a copy of Patty McGill Smith's article, "You Are Not

Alone"; and

(9) copies of "Baby Care" and "Touch: The Language of Love," both provided by Johnson and Johnson.

Items one through seven were developed by HRP staff. Copies of all except the Johnson and Johnson booklets are found on pages 30 through 56 of this report.

The HRP lending library includes books and articles on general child development and guidance as well as information on specific handicaps and parents' experiences. The library is located at the group class site and books can be checked out for as long as needed. Also in the classroom is a collection of most of the toys and equipment used in the program, all of which can be borrowed by families when appropriate to work on a specific skill. If families are not able to attend group classes, the developmental specialist can leave appropriate equipment at the end of a home visit and retrieve them when they are no longer needed. A particular effort is made to loan appropriate toys to families who are unable to purchase many toys, but income level does not determine who may borrow from the toy collection.

Each month the HRP director prepares a very brief newsletter with items of interest to Project parents. While primarily containing news of HRP events and developments, occasional letters have included general information and notices of other events of interest. In recent months, information about the progress of the HRP funding search and pleas for letters to government and United Way officials have been included. Sample copies of newsletters are included on pages 57 through 61 of this report.

PARENT SUPPORT GROUP

The HRP has tried several different approaches to establishing a parent support group, none of which has yet proven entirely successful. In the earliest months of the program, families were encouraged to attend the monthly parents' meetings conducted by the social worker at Huntsville Hospital, site of the regional neonatal intensive care unit where many HRP children spent their first several months of life. These meetings, held on Sunday afternoons, were also attended by the HRP social worker, who noticed that for three successive months she was the only HRP-affiliated person present. When she asked parents if the hospital's meetings were not convenient for them, responses generally followed one of two trends: (1) "We want to put our hospital experience behind us" or (2) "Parents of children still in the NICU are concerned with survival today and tomorrow. That used to be our worry too, but now we have more long-term concerns."

With that information to start with, the HRP social worker surveyed parents about which concerns they would like to see addressed in meetings and began separate meetings for HRP families. Responses to the survey showed an almost even split in preferences for weeknight or Sunday afternoon meetings. Because several of the 12 enrolled families lived an hour's drive from Huntsville, the social worker decided that Sunday afternoon would probably be the most convenient time for the most families. Babysitting was provided by volunteers or staff members at the site.

The best attended "meeting" in this series was a November party, a purely social function and the first gathering of HRP parents, attended by most of the enrolled families. Following that, presentations were arranged on issues about which parents had indicated a need for more information. A staff member from the mental health center spoke on discipline, a psychologist addressed developmental delays and local services for delayed and handicapped children, and the HRP director arranged a film to begin a discussion on normal infant and toddler development. Attendance at these meetings ranged from three to five parents. While such attendance was not surprising in a program of only 15 families, Project staff members were reluctant to invite speakers when attedance was so uncertain. Regular meetings were suspended for the summer while plans were made for group classes with a parent-meeting component.

The establishment of group classes has been described in the "Services to Children" section of this report. The original plan was to schedule approximately six children and their parents to see the speech and occupational therapists during one hour, followed by an hour's parent meeting with the developmental specialists and a regular volunteer caring for the children in a separate room. However, this back-to-back format, which works so well in the Houston, TX, program we had observed, presented almost immediate problems for the HRP. Two reasons were rather quickly identified:

(1) The Houston program serves older children (18 months and older) in group classes, so some small group activities are possible, as is a group snack time. Most of the HRP children

were less than 12 months old, making group activities inappropriate. Since this was the time set aside for individual consultation with the speech and occupational therapists, one hour was not sufficient for six children.

(2) Also because of the age of the children, most were ready for bottles or nursing and then for sleep about the time that the parents' session was to begin. Consequently, parents were reluctant to stay for the second hour or to leave their children in the care of someone else. Having a parents' discussion in the room with the children was also tried but did not prove satisfactory.

The decision was then made to abandon, at least for a time, the idea of regular parent meetings and, instead, to try to encourage informal parent interaction during the therapists' portion of group classes. The number of children scheduled in an hour was reduced, creating a less pressured pace during the hour. The mats that designate each child's place were arranged closer together and staff members made a more conscious effort to encourage parent-to-parent conversation. Children had already been assigned to groups according to their disabilities and developmental levels, a policy that has proven to encourage parent interaction. Some parents who had met while their children were in the NICU have renewed acquaintances during this time; one group of mothers of children with Down's syndrome have occasionally gone to lunch together following their group class. While this informal interaction does not serve the same purpose as informational parent meetings, it may be the best possible balance between parents' needs, pressures and time constraints.

Two sets of HRP parents, one in Huntsville and one in a county almost an hour's distance, have requested help from the HRP in starting a parent-organized support group. HRP staff members have encouraged the formation of such groups, formal or informal, and have publicized such efforts in the monthly newsletter and during home visits. At last report, the group in the outlying county was beginning to take shape while the Huntsville parents were still trying to find others interested in forming such a group.

CONTACTS WITH OTHER AGENCIES

As the children mature and their needs become more clearly identified, concurrent or successive placement in another program often becomes appropriate. For children living in all but Jackson County, placement in another program by age three is almost always made. The Project staff members try to remain cognizant of all programs serving young children with special needs in north Alabama so appropriate referrals can easily be made.

Transition into another program often causes anxiety for parents, but since a major focus of the HRP is to help parents feel more competent in managing the needs of their children, Project staff members encourage parents to make the initial contact with other agencies. Parents are always given the information they need to make such a contact (full name of the program, address, phone number, name of contact person) and, if necessary, are coached in what to say, but the HRP staff feels that it is important for parents to assume this responsibility.

The HRP director always offers to make a follow-up call but usually only makes the initial contact if it is evident that the parent does not feel confident enough or is otherwise unable to do so.

When a child has left the HRP for another program, Project staff members make sure that the parent knows that he or she can still contact the HRP for support while the parent gains confidence in the staff members in the new program.

Madison Area

High Risk Project

Huntsville, Alabama

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Grant No. G008302260
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Special Education Programs
Handicapped Children's Early Education

A Division of Madison Country ARC
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Photographs compliments of
Photography by Saint

HISTORY-PHILOSOPHY

Madison Area High Risk Project was funded in October 1983 to serve children ages 0-3 who are "at risk" of developmental delays.

The High Risk Project defines "at risk" as infants who seem less likely than others to make progress and to achieve their full potential.

The philosophical approach of the project is that medical services alone are often not enough to facilitate optimum development of high risk infants. For such infants and their parents, a concentrated program of educational intervention is required. The goal of this educational intervention project is to promote optimal development of high risk infants through implementation of special therapy activities focused on parent-child interactions.

SERVICES

- Multidisciplinary team approach to parent and infant training.
- Individual home and/or center based activities.
- Group activities with parents and families.
- Affiliation with local Parent-to-Parent Organization.
- Coordination with Follow-Thru Clinic and other Agencies.
- Parent resource information.
- Periodic screening and assessment.
- Provides information to enhance community awareness of infants "at risk" of developmental delays.

CURRICULUM

— Focuses on increasing cognitive, social, language, and motor development of children.

— Comprehensive curriculum model.

— Individual Education Programs are developed based on the child's strengths and weaknesses.

— Parent training is provided to enhance teaching skills and parent-child interaction.

EARLY WARNING SIGNS

These early warning signs may indicate that your child is "at risk" of developmental delays.

After reviewing this check list, if you suspect your child has a delay we urge you to seek help immediately.

SEEING

If your child:

— does not look at toys or people and try to reach for them

— frequently rubs his eyes

— has red, watering eyes or encrusted eyelids

— sometimes or always crosses one or both eyes

— does not notice distant objects

HEARING

If your child:

— does not startle to loud noises

— does not turn to face sounds and noises by six months

— has frequent earaches, running ears or running nose

— does not understand spoken conversation or directions

— talks in unusually loud voice

TALKING

If your child:

— does not babble and coo as an infant

— cannot say the names of a few people and toys by age two

— does not tell you about two things that happened to him that day by age three

— does not talk in short sentences by age four

IS YOUR CHILD "AT-RISK"?—REFERRAL

MOVING

If your child:
- — us unable to sit by age one
- — is unable to walk by age two
- — is unable to throw and kick a ball by age three
- — is unable to run by age four
- — is unable to hop on one foot by age five

THINKING

If your child:
- — does not respond to his name by age one
- — does not point to eyes, ears, nose, and mouth by age two
- — does not know ''big'' and ''little'' by age three
- — does not know three colors by age four
- — does not count to five by age five

HELPING

If your child:
- — has trouble sucking a bottle as a newborn
- — does not use a spoon by age two
- — is not out of diapers by age three
- — does not play cooperatively with other children by age four
- — cannot dress himself by age five

HOW TO REFER OR OBTAIN ADDITIONAL INFORMATION:

call or write

MADISON AREA HIGH RISK PROJECT
P.O. BOX 1063
HUNTSVILLE, AL 35807
(205) 539-2266

MADISON AREA HIGH RISK PROJECT
P.O. BOX 1063
HUNTSVILLE, AL 35807

Madison Area
High Risk Project

PROGRAM GOAL:

The goal of the High Risk Project (HRP) is to help parents help their children achieve their full potential. Parents and HRP staff members work together to encourage the children to develop new skills in an appropriate order. All suggested activities can be worked into normal daily routines and can be done by any parent or other adult. If needed, parents are given special instructions in doing any particular activity with their child.

CHILDREN SERVED:

The HRP works with children
--birth to 36 month old who are (1) showing delays in any area of development; or (2) diagnosed as having a condition known to cause developmental delays.
--three to five years old who meet one of the above conditions and for whom no other appropriate program is available.

Each child must have an enrollment form completed by his/her parent and a medical referral form completed by a physician.

PROGRAM SERVICES:

--Home visits every other week by a home teacher/developmental specialist.
--Small group classes where child and parent are seen by speech therapist and occupational therapist. Group classes are held in the First United Methodist Church, Huntsville.
--Individual speech and occupational therapy for children whose attendance at group classes is impossible. Individual sessions are held at the Opportunity Center in Huntsville.
--Lending library of toys and parents' books.

Children may participate in one or more of the program services, depending on their needs and their families' desires.

INDIVIDUAL EDUCATION PLAN:

Two different assessment forms are used to keep track of each child's skill development. After the initial assessment is completed, parents and HRP staff members together set goals for the child. These goals are written into an Individual Education Plan (IEP) and re-checked frequently. When a new skill is learned, a new goal is set. In this way, the IEP "grows" with the child.

COST:

The High Risk Project is supported by a model development grant from the U.S. Department of Education. There is no fee to families participating in the HRP.

For further information or an enrollment application, contact Susan Smith
Madison Area High Risk Project, PO Box 1063, Huntsville, AL 35807.
(205) 539-2266.

Madison Area
High Risk Project

OPPORTUNITY CENTER

513 Washington Street
Huntsville, AL 35801

P. O. Box 1063
Huntsville 35807

(205) 539-2266

Parents' Handbook

Madison Area

High Risk Project

The Madison Area High Risk Project (HRP) is a federally funded program with two goals:

(1) developing a model program that can be replicated in other parts of the country; and

(2) providing appropriate services to families of children 0 to 36 months of age who are at high risk of having developmental problems and/or delays. The goal of such services is to support the families and help these children achieve their full potential.

The High Risk Project is sponsored by the Madison County Association for Retarded Citizens. The ARC Board is the policy-making board for the Project. The HRP also has its own Advisory Board composed of pediatricians, special educators, therapists, parents and other concerned individuals.

The HRP office is at the Opportunity Center. Office hours are 8:00 AM to 4:30 PM.

There are no fees to families participating in the High Risk Project.

No person shall be excluded on the grounds of race, creed, color or natural origin from participation in, be denied the benefits of, or be otherwise subjected to discrimination under this program.

PROJECT STAFF

The HRP staff consists of:

(1) a Project director who oversees both the model development and the direct services aspects of the program ; and

(2) two developmental specialists who conduct an on-going assessment of the child's development and suggest activities for parents to do between visits.

Speech, physical and occupational therapists are under contract to the Project. The Opportunity Center's director, administrative assistant and preschool coordinator also contribute a portion of their time to the Project.

PROGRAMMING

There are several components of the High Risk Project. Individual families may participate in different combinations of these components:

(1) home visits--generally speaking, the developmental specialist visits the home every other week for approximately an hour of skill-developing activities and assessment;

(2) group classes--the parent(s) and child attend with a small group of other children. Group classes are usually scheduled for the week between home visits. These classes are described more fully on the next page;

(3) individual speech therapy for children who are unable to attend group classes; and

(4) individual physical/occupational therapy for children who are unable to attend group classes.

All programming is individualized, with short- and long-term goals set for each child. At each session, the parent is given a list of activities to do with the child to help him/her reach the next developmental goal. It is an accepted fact that no child will make significant progress on only two to six hours of special programming per month. The entire success of the program and the child's continuing progress depend on the parent's willingness to provide this continuity between sessions.

GROUP CLASSES

Group classes are held in Room 504 on the second floor of the First United Methodist Church's Wesley Center at 111 Green Street, across the street from the church's main building. The map at the end of this booklet should help you find it.

The HRP group classes are designed so that one developmental specialist teams up with the occupational therapist each session while the other works with the speech therapist. At least initially, each child spends some time with both the OT/specialist team and the speech/specialist team each session. We try to schedule the children within a group so that developmental levels are somewhat similar, so the teams will sometimes work with two children at a time. This does not mean that we want to encourage comparisons between children, though. Each child in the HRP is at his or her own developmental level and proceeding at his or her own pace, so pressuring a child to "catch up with Johnny" can mean that important developmental steps get skipped.

For many of the HRP children, these group classes will be the first time they have been around several other children of similar age or level, so we know to expect some interesting reactions, particularly among the toddlers. The approach that we use to guiding behavior is to ignore inappropriate behavior (for example, tantrums) and to reward appropriate behavior with smiles and pleasant personal contact. Destructive or hurting behavior (throwing toys, pinching, etc.) will be stopped by parent or teacher and the child will be taught more acceptable behavior.

The group classes also include time for parents to get together and share experiences and insights. Parents are encouraged to bring interesting magazine articles, toys, etc., to share with others. HRP staff members will also be bringing articles, etc., that we think might be of interest. The book and and toy lending libraries are open during group classes.

The Health Department expects us to have immunization records on all children in the group classes. The HRP has a handy folder for that purpose or we can copy whatever other record you have.

Parking for the group classes is a little tricky. The First United Methodist Church has a small parking lot, with an entrance on Randolph Street, which we can use except on the second Monday of each month. (We will note these days on your calendar if you have group classes on the second Monday.)

Public (metered) lots are marked Ⓟ on the map. There is also metered parking on Green Street in front of the building.

Other nearby lots where we have permission to park are also noted on the map. They are:
Ⓐ across Clinton Street from the Central Church of Christ; and
Ⓑ the gravel lot off Randolph Street behind the Central Presbyterian Church.

On rainy days, HRP staff will meet you under the overhang on the Wesley Center building and take the children out of the car while you go and park. You will want to be running five to ten minutes early on those days so you can get parked and get back to the class in time to begin at 9:30.

ADMISSION PROCEDURES

Referrals to the HRP may come from any concerned individual. After telephone screening, a home visit is scheduled by the Project's director to discuss the program and the child's needs. If the parent decised to apply, he/she will be asked to sign release forms so that the HRP can obtain the needed medical referrals and records, including a description of disabilities and limitations. When all required records have been received, the Project's Placement Committee meets to determine the appropriateness of the program for the child.

If space is currently available in the program, the child may begin receiving services immediately while being scheduled for a formal assessment of skill level within thrity days. If there is no space available in the program at the time, the child's name is placed on a waiting list.

WHAT YOU CAN EXPECT FROM THE PROJECT

--high quality interaction with professionals concerned about you and your child.

--a monthly calendar of your child's scheduled home- and center-based sessions, sent to you 2 weeks in advance.

--frequent news and information about the project and other items of interest.

--an opportunity to participate in Parent Support Group activities, including social events and discussions by professionals in the field.

--access to an array of resources, e.g., books and toys to lend, free pamphlets, etc.

--an increased sense of competence in helping your child attain his/her developmental goals, the result of having worked as part of the Project team.

THE PROJECT NEEDS FROM YOU

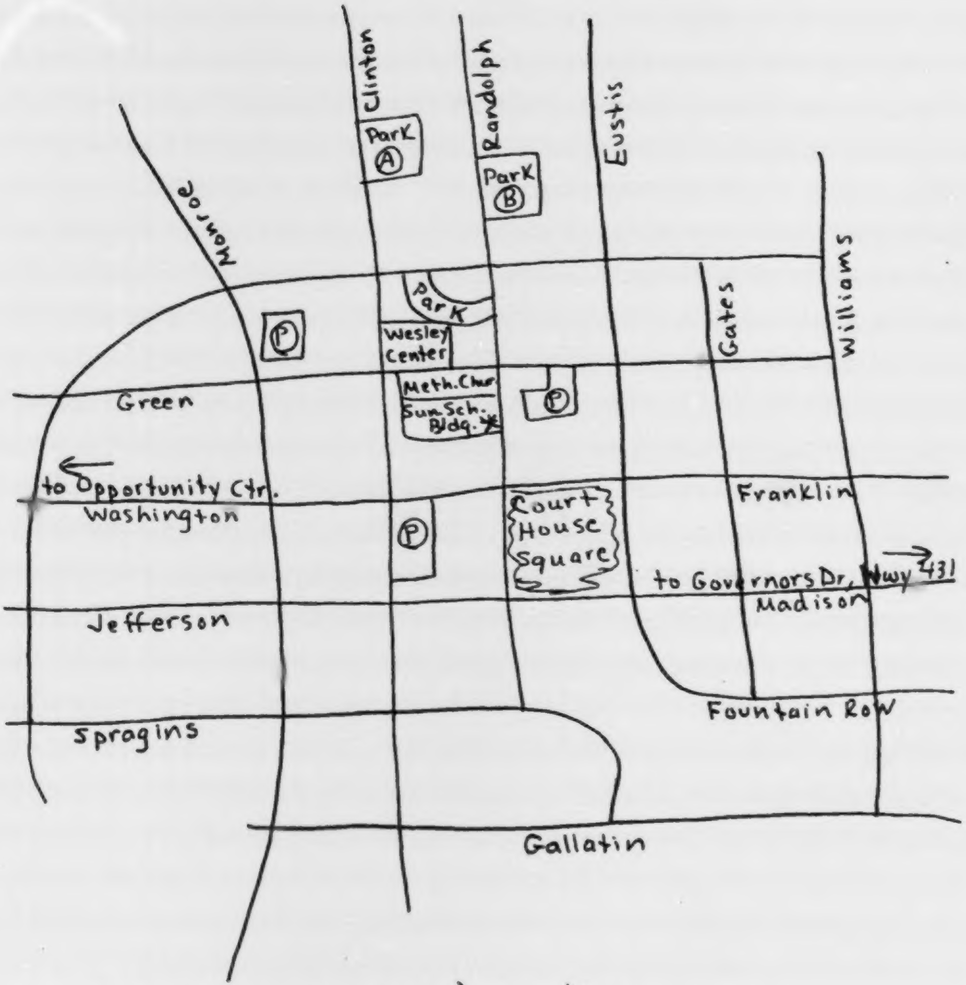
--your wealth of knowledge about your child's personality, learning style, capabilities, difficulties, etc.

--cooperation in working out a program and schedule that will meet your, your child's and the Project's needs.

--promptness and consistency in keeping appointments, and early cancellations of sessions you cannot attend.

--your signature on release for medical records and other information needed to determine the continuing appropriateness of the program for your child.

--immediate notice of changes of address and/or telephone numbers.


Clinton
Randolph
Eustis
Monroe
Park Ⓐ
Park Ⓑ
Williams
Gates
Park
Ⓟ
Wesley Center
Meth. Chur
Sun. Sch. Bldg. *
Ⓟ
Green
to Opportunity Ctr.
Washington
Ⓟ
Court House Square
Franklin
to Governors Dr, Hwy 431
Madison
Jefferson
Fountain Row
Spragins
Gallatin

Ⓟ Public (metered) parking

Ⓐ Parking lot across Clinton St. from
Central Church of Christ

Ⓑ Gravel parking lot on Randolph St.
behind Central Presbyterian Church

Madison Area
High Risk Project

PARENTS' LIBRARY

The following books belong to Susan Smith

1. Growing Wisdom, Growing Wonder, By: Gregg & Knotts
2. Childhood Illness , By: Shiller
3. The Magic Years , By: Fraiberg
4. Baby Learning Through Baby Play, By: Gordon
5. A Guide To Discipline , By: Stone
6. A Child Is Born, By: Nilsson
7. The Mother's Almanac, By: Kelly & Parsons
8. Surviving Fights with Your Brothers and Sisters, By: Wilt
9. Partners in Play, By: Singer & Singer
10. On "How Do Your Children Grow?", By: LeShan
11. Help: A Handbook For Working Mothers, By: Greenleaf & Schaffer
12. Positive Parenthood, By: Graubard
13. Every Child's Birthright, By: Fraiberg
14. Freedom & Beyond, By: Holt
15. The Playgroup Handbook, By: Broad & Butterworth
16. Freedom to Learn, By: Rogers
17. The New-Fashioned Parent, By: Berman
18. What Makes Me Feel This Way?, By: LeShan
19. Growing Up Free, By: Pogrebin
20. The School Book, By: Postman & Weingartner
21. Preparing Your Child For Reading, By: Tinker
22. How to Raise An Independent Child, By: Gould

Madison Area
High Risk Project

The following books belong to the High Risk Project:

23. All Children Grow and Learn, By: Spitalnik & Rosenstein
24. The Baby Book, By: Wyeth Laboratories
25. Child Health In America, By: U.S. Dept. Health, Education, Welfare
26. Delivery and Beyond, By: Hoffman, Gerbie, Edoff & Vitt
27. The Early Needs of Children with Cerebral Palsy, By: Blackman & Hea
28. An Education Handbook for Parents of Handicapped Children, By: Mopsik & Agard
29. Genetic Screening for Inborn Errors of Metabolism, By: Levy
30. Guidelines for Early Intervention Programs, By: Uni. of Utah
31. Handling the Young Cerebral Palsied Child at Home, By: Finnie
32. Help for Parents of a Handicapped Child, By: Roberts
33. The Improved Pregnancy Outcome Project, By: Goldenberg & Koski
34. Information and Referral, Huntsville/ Madison Co.
35. Learning Together: A Guide for Families with Genetic Disorders, By: U.S. Dept of Health and Human Services
36. The Needs of Children with Disabilities, By: Healy
37. One Step At A Time, By: Scheiber
38. Parents Guide, Developmental Support of Low Birthweight Infants, By: Thurber & Armstrong
39. Partners, A Guide to Working with Schools for Parents of Children with Special Instructional Needs, By: Lillie & Place
40. Premature Babies, A Handbook for Parents, By: Nance
41. Raising the Exceptional Child, By: Zuckerman & Yura
42. A Readers Guide for Parents of Children with Mental, Physical, or Emotional Disabilities, By: Moore, Morton, Southard

43. Research Issues in the Assessment of Birth Settings, By: National Research Council

44. Research Priorities in Maternal and Child Health, By: Klerman, Editor

45. A Very Practical Guide to Discipline with Young Children, By: Mitchell

46. Your Premature Baby, By: Henig & Fletcher

47. My Friend David, By: Edward and Dawson

48. Teaching Your Downs Syndrome Infant, By: Hanson

49. Free Stuff for Kids, By: Meadowbrook Press

50. Caring About Kids series (8 titles, including "Pre-term Babies," Stimulating Baby Senses," "The Importance of Play"), By: National Institute for Mental Health

51. When Something is Wrong with Your Baby, By: Pieper

52. Straight Talk: Parent to Parent, By: Pieper

53. The Teacher and the Child with Spina Bifida, By: Pieper

54. The Child with Spina Bifida, By: Swinyard

55. An Introduction to Spina Bifida, By: McLone

56. Parenting Preschoolers: Suggestions for Raising Young Blind and Visually Impaired Children, By: Ferrell

57. Portage Parent Program (readings), By: Boyd and Bluma

58. Hope for the Families, By: Perske

59. We All Come in Different Packages, By: Konczal and Pesetski

60. Developmental Handicaps in Babies, By: Brown

61. Like Me, By: Brightman

62. So Your Child Has Cerebral Palsy, By: Joel

63. The First Twelve Months of Life, By: Caplan

64. The Second Twelve Months of Life, By: Caplan

65. Practical Advice to Parents: A Guide to Finding Help for Children with Handicaps, By: Scheiber and Moore

66. What Everyone Should Know About Educating Handicapped Children: A Guide to P.L. 94-142 (booklet)

67. Toddlers and Parents, By: Brazelton

68. Easy-To-Make Aids for Your Handicapped Child, By: Caston

69. The Retarded Child: Answers to Questions Parents Ask, By: Atwell and Clabby

70.

70. Infants and Mothers, By: Brazelton

71. Lisa and Her Soundless World, By: Levine

72. Teaching Your Down's Syndrome Infant, By: Hanson (2 copies)

FOLDERS OF INFORMATION (MAGAZINE ARTICLES, BOOK EXCERPTS, ETC.) ON THE FOLLOWING TOPICS ARE AVAILABLE IN THE HIGH RISK PROJECT'S LENDING LIBRARY.

Aggression

Alcoholism in the family

Anger

Anxiety/fears

Babysitters

Birth

Child abuse

Choosing a child care center or preschool

Chores

Coping with disappointments, problems

Death

Discipline, guidance

Divorce/separation

Fairness

Friendships

Grandparents

Hospitilization

Holidays

Honesty, lying

"How to answer your kids' most outrageous and ticklish questions"
"Hyperactivity"

Imaginary companions

Kindergarten readiness

"Learning how to leave your baby alone"

Moral development

Nutrition

Only children

Parenthood

Security blankets, thumbs, etc.

Self-concept

Separation anxiety

Sex education

Sex roles

Sharing

Shyness

Siblings

Single parents,remarriage

Sleep, bedtime problems

Spouses

Stress in children

Taking children shopping

Tattling

Teaching children how to manage money

Television

"The most important things parents can teach a little child"
Things to do

Toilet training

"What to do when your child says, 'No, I won't'"
Working parents

HRP GLOSSARY OF FREQUENTLY-USED TERMS

Ambulatory - commonly used to refer to an individual who is able to walk.

Amniocentesis - a procedure for analysing factors in the amniotic fluid of the uterus to determine certain aspects of fetus development. (Can be used in identification of Down's Syndrome, Spina Bifida, and other congenital defects.)

Aphasia - the loss of language, usually due to a stroke.

Asphyxia - condition in which the body is deprived of oxygen as in smoke suffocation or drowning. If deprivation is prolonged, a coma may result, with accompanying brain injury or death.

Asymmetric Tonic Neck Reflex (ATNR) - when baby's head is turned to one side, arm and leg on "face" side straighten while arm and leg on "skull" side bend. Natural reflex which appears when stimulated; usually disappears about 5 months of age.

At Risk - term applied to children with a high potential for future learning problems but who have not been positively identified as such.

Auditory - pertains to the sense of hearing.

Babbling - stage which occurs early in language development and is characterized by the repetition of sounds.

Baby Talk - speech characterized by patterns and pronunciation imitating or carried over from earliest speech.

Balance Reactions - compensatory movements to maintain balance.

Bilateral - when used in reference to the body, it refers to involvement of both sides (both arms, both legs, etc.)

Cerebral palsy - inability of the brain to properly control the muscles.

Chromosome - basic unit in the nucleus of the body cell which carries the genes or hereditary factors.

Chronological Age (CA) - the amount of time, usually expressed in years and months, that has elapsed since an individual's birth.

Cognitive - descriptive term referring to the mental process of memory, reasoning, comprehension, and judgment.

Congenital - describes presence of condition or characteristic in an individual at birth.

Crawling - scooting forward or backwards on stomach, using arms and/or legs for movement.

Creeping - movement forward or backward on hands and knees - see also Four-Point Stance.

Decibel (db) - unit of measurement expressing intensity of sound; a unit of hearing or audition.

Developmental Delay - significant lag in normal progression of skills.

Diagnostic Test - measure designed to analyze or locate an individual's specific areas of weakness or strength to receive attention in future instruction.

Due Process - principle of law guaranteeing a meaningful opportunity to protest and be heard prior to official action. In special education, this assures parents and handicapped children a hearing before placement or reassignment.

Dyslexia - an impairment in reading ability, or partial inability to read; often associated with cerebral dysfunction or minimal brain dysfunction.

EEG - a mechanical tracing made by an electroencephalograph that graphically shows electrical output of brain waves. Useful in studying seizures accompanying brain injuries.

Etiology - the study or assignment of causes, reasons, or origins; especially of diseases or conditions such as behavior/learning disorders.

Evaluation - a factual appraisal or estimation of certain specific characteristics, such as intelligence, personality, or physical aspects of an individual.

Exceptional Child - one who deviates markedly, either above or below the group norm, in mental, emotional, physical, social, or sensory traits, to a degree that special services are required to help the child profit from educational experiences.

Extended Family- term referring not only to parents and siblings but also to grandparents, aunts, uncles, cousins, etc.

Extension - act of straightening leg, arm or other body part. A certain amount of extension is necessary for walking and other normal body movements. Hyperextension (too much)inhibits coordinated movements.

Eye-Hand Coordination - ability of an individual to combine and coordinate functions of the eyes and the hands in carrying out manipulative activities involving the hands.

Feces - waste matter discharged from the body during bowel movements; stool.

Fine Motor - awareness of and skill involved in small muscle activity. Examples: pointing, grasping, writing, using scissors.

Flaccid - low or minimal muscle tone in which the muscle is flabby, soft, weak, and considered unhealthy. Also called hypotonia.

Flexion - act of bending leg, arm or other body part.

Four-Point Stance - kneel on hands and knees in creeping position.

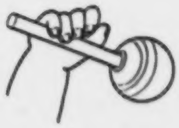
Functional Hearing Loss - inability to hear stemming from psychological problems rather than from impairment of the ear or auditory mechanism.

Functionally Blind - describes the condition of visual impairment in which the individual is not able to use print as a reading medium.

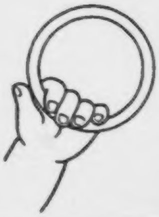
Genetic - pertaining to heredity, or features transmitted by chromosome from parents to their offspring.

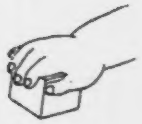
Grasps - (in order of appearance)
1. raking--with edge of hand down on surface, using fingers against the palm to pick up an object.

2. ulnar palmar--using the ring and little fingers against the heel of the palm to pick up an object; no use of the thumb.

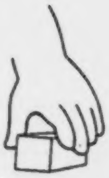


3. palmar--using all the fingers against the palm; no use of thumb.



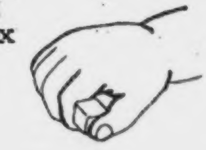


4. radial palmar--using thumb in partial opposition to fingers, but still using palm.

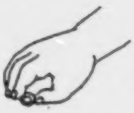


5. radial digital--using thumb in opposition to three middle fingers; middle fingers working as a unit.

6. inferior pincer--using thumb and side of the index finger to pick up a small object.



7. neat (or fine) pincer--using tips of thumb and index finger to pick up a small object.



(Illustrations from HELP Activity Guide)

Gross motor - awareness of and skill involved in large muscle activity. Examples: rolling, crawling, walking, running, throwing and jumping.

Handicap - the result of any condition or deviation, physical or mental, that inhibits or prevents achievement or acceptance.

Head Lag - head falls behind when child is pulled up from a supine to a sitting position.

Heart Defect - any of anumber of conditions resulting from malformations, mechanical imperfections, or injuries to the heart, its muscles, or vessels leading to and from it.

Hearing Aid-Any of a number of devices used for collecting, conducting, and amplifying sound waves, to help the user utilize his or her hearing capacity to the maximum.

Hertz - A unit of measurement of frequency or vibrations per second of sound waves, formerly, cycles per second.

Horizontal - A line drawn from side to side.

Hypertonia - Condition characterized by excessive muscular tension.

Hypotonia - Decreased muscle tension, affecting posture and the initiation of movement. Also called flaccid.

Individual Education Plan (IEP) - A written plan of instruction for each child receiving special services giving a statement of the childs' present level of educational performance, annual goals, short-term objectives, specific services needed by the child, dates when these services will begin and be in effect and related information. IEPs are required by Public Law 94-142 for all children receiving special education services.

Intervention - a technique used in teaching exceptional children, in which existing unproductive, or undesirable behavior is intercepted and directed toward other behaviors that are more productive or desirable.

I.Q. - the numerical figure commonly used to express level of mental development - computed by dividing mental age by the chronological age and multiplying by 100.

Inversion - turning upside-down. A feet-over-head position.

Label - a generalized name to a handicapping condition such as mentally retardation, cerebral palsy, learning disabilities.

Language - any system of words or symbols and the rules for putting them together to form a method of communication among a group of individuals.

Least Restrictive Environment - concept expressed by the courts in the 1970s in essence saying that disabled persons should be educated or served in the most nearly"normal"environment possible.

Mental Age (MA) - level of an individual's mental ability expressed in terms of the average chronological age of others answering the same number of items correctly on a test of mental ability.

Midline - imaginary line going down the middle of the body.

Mild hearing loss - an impariment demonstrated by difficulty in hearing faint sounds. Such an individual needs favorable seating arrangements and may benefit from speech, reading, vocabulary, and language instruction. Described generally as 27-40 db loss.

Multidisciplinary - more than two professions represented or contributing to a common objective, such as a screening commitee consisting of a special educator, a medical doctor, a psychologist, a social worker, and a school administrator.

Multihandicapped - having a physical or sensory handicap plus one or more additional handicaps that inhibit response to education in the regular classroom.

Muscle Tone - the normal degree of tension in a muscle; the resistance of a muscle to passive stretching or elongation.

Occupational Therapist - graduate of an occupational therapy program and approved by the Council on Medical Educational of the American Medical Association, or an individual who has the equivalent of such education and training.

Otitis Media - Inflammation of the middle ear which may be accompanied by pain, fever, interference with hearing, and problems with balance.

Percentile - A rank in a distribution at or below which fall the percent of cases indicated by the percentile.

Perceptual Motor - Term used to refer to interaction of the various aspects of sight, hearing, etc., with motor activity.

Perinatal - Occurring immediately before, during or immediately after birth.

Physical Therapy - Treatment of disabilities by using massage, exercise, water, light, heat, and certain forms of electricity all of which are mechanical rather than medical in nature. PT is practiced by a professionally trained physical therapist under the referral of a physician.

Pivot Prone - While on stomach, raising head, shoulders, arms and legs off ground.

Post-natal - Occurring after birth.

Prenatal - Occurring before birth.

Prone - Lying on stomach.

Protective Extension - Normal reaction of catching with the arms when falling.

Psychometry - The field of evaluation or measurement of psychological functioning by means of standardized tests. A person qualified to do this is a psychometrist.

Public Law 94-142 (P. L. 94-142) - A federal law passed in 1975 and often described as the "Bill of Rights for the Handicapped". It provides definitions of the various handicaps; mandates free and appropriate public education for handicapped persons; and establishes priorities for special education services, protective safeguards and procedures for developing the mandatory IEP.

Range of Motion - Amount of movement in joints.

Readiness - Point in a child's maturation at which he or she has developed the sensory and intellectual skills to be able to learn the task or skill involved.

Referral - Process of informing a clinic, school, medical doctor, or other appropriate specialist about an individual for the purpose of evaluation or treatment.

Reflex - Any consistent muscular or neurological response performed involuntarily as a result of a sensory stimulation.

Rehabilitation - Process of helping a nonproductive or deviant person toward restoration or the desired standard, through education or retraining, often vocational or physical in nature.

Rehabilitation Act of 1973 - Comprehensive piece of Federal Legislation which expanded federally funded rehabilitation services to the severely disabled.

Reinforcement - Any consequence of behavior that increases the probability of occurrence of the behavior it follows.

Rooting Reflex - Response to touch on side of face, as in looking for nipple.

Screening - Abbreviated testing procedures by a variety of disciplines conducted on a large scale to locate children requiring more detailed testing or specialized teaching.

Seizure - An outward expression of abnormal brain discharges which may be expressed in several forms of behavior, from mild to severe in intensity.

Self-Help Skills - Knowledge that allows one to carry out daily living tasks without assistance or with a minimum of assistance. These skills are included in curricular requirements of programs for the handicapped.

Shunt - A technique involving implantation of a tube to drain or provide a bypass for excess cerebrospinal fluid, as in hydrocephalus.

Social Worker - Professionally trained person who serves the handicapped, deprived, troubled, poor, neglected or abused, and similarly in need, by collecting information and coordinating and dispensing services.

Spastic cerebral palsy - the most usual form of cerebral palsy, characterized by muscle stiffness.

Special Education - Broad term covering programs and services for exceptional children who deviate so far physically and mentally, or emotionally from the normal that they require unique learning experiences, techniques, or materials in order to be maintained in the regular classroom, and specialized classes and programs if the problems are severe.

Speech Pathology - Field of diagnosing and treating speech problems and lack of speech development.

Speech Therapy - A planned program of speech improvement and correction for individuals who are handicapped in language communication and speech adjustment and are not expected to improve solely through normal maturation.

Splinter Skills - Skills learned out of sequence without necessary prerequisites. Example - Walking before crawling.

Standardized Test - A measure that is administered and scored by uniformed objective procedures and for which norms have been established so the scores of anyone completing the test can be compared to the norms.

Supine - Lying on the back.

Symmetric Tonic Neck Reflex (STNR) - reflex triggered by either flexing or extending the neck of a baby in the "all fours" position. Extending neck (looking up) causes extension of arms and flexion of hips. Flexing neck (looking down) causes arms to flex and hips to extend.

Tactile - Refers to the sense of touch.

Tactile Hypersensitivity - Excessive sensitivity to touch, textures.

Unilateral - On one side only - used to refer to conditions on only one side of the body.

Ventral suspension - A position in which the child is held horizontally in mid=air, supported under the stomach.

Verbalizations - words or attempts at making words

Vertical - A line (imaginary or real) drawn up and down.

Vocalizations - Sounds such as cooing, babbling, etc.

Madison Area
High Risk Project

The Madison Area High Risk Project serves children with a wide range of conditions and prognoses. Some of "our" children have been diagnosed as having a condition that will have life-long effects on their development; others are delayed in their development at this early age but may well catch up as they grow. Whichever description currently fits your child, you need to know what legal protections you and your child have under federal and state laws. Much of the attached information applies primarily to your child's attendance in public schools, but guarantees of your right to be involved in all decisions about your child's education apply in the High Risk Project and any other program in which your child participates.

We wish we could say that every educational agency you will ever come in contact with follows these procedures without fail. In practice, we're all fallible and steps occasionally get skipped, especially in the public schools, with the large number of children they serve. We have gathered this information from several sources and provide it in hopes that it will be of help to you in your role as an advocate for your child. If any of it needs explanation or you need further information, please ask us.

P.O. Box 1063 • Huntsville, Alabama 35807
A Division of the Madison Co. ARC

Know Your Rights — And Use Them!

Everyone has the right to learn — to his fullest potential

The Education for All Handicapped Children Act (Public Law 94-142) requires that public school education be made available to *all* children, including the most severely disabled. Section 504 of *The Rehabilitation Act* makes clear that every handicapped child must have an equal opportunity for education. Discrimination is forbidden.

But laws don't enforce themselves. It takes hard work, changes in old ways of thinking and acting.

The best way to begin is to know the new laws. What rights do they establish? How can you use them?

What do the laws say?

The Education for All Handicapped Children Act (P.L. 94-142) was passed by Congress in 1975 and went into effect September 1978. This landmark legislation makes it possible for states and localities to receive federal funds to assist in the education of physically, mentally and emotionally handicapped children. In order to receive their share of P.L. 94-142 funds, states must assure these rights:

- All handicapped children, regardless of the severity of their disability, will receive a free, appropriate education — at public expense.
- Education of handicapped children will be based on a full and fair evaluation and assessment of the specific, unique needs of each child.
- Individualized education programs (IEPs) will be drawn up for every child found to be eligible for special education, stating precisely what kinds of special education and related services each child will receive.
- Related services for handicapped children include recreation, counseling, transportation—and other specific activities that meet individual needs, such as speech pathology services and physical and occupational therapy.
- Parents have the right to participate in every decision related to the education of handicapped children.
- Parents must give consent for any change to be considered; parents and teachers must be included in conferences held to draw up individualized programs; parents must approve these plans before they go into effect
- The right of parents to challenge and appeal any decision related to identification, evaluation and placement of their child must be fully protected by clearly spelled out due process procedures.
- According to law, special education includes classroom instruction, physical education, home instruction, instruction in hospitals and institutions, and vocational education that is designed to meet the unique needs of a handicapped child.

What is Section 504?

Section 504 has been called the civil rights law for handicapped persons. It has vast coverage. It protects the rights of handicapped people of *all* ages and in all areas of life. It prohibits acts of discrimination against disabled persons by any agency, organization or program receiving federal financial assistance.

Agencies that persist in acts of discrimination face loss of federal funds. This includes colleges and universities, vocational education and adult education programs, state and local governments, places of employment, hospitals and clinics, public and private groups of all kinds which receive federal financial assistance. Section 504 assures equal opportunities for handicapped children in schools receiving federal funds — preschools, elementary and secondary schools, and post-secondary schools.

How does 504 affect the educational rights of handicapped persons?

Regulations for 504 written by the U.S. Department of Health, Education and Welfare make clear that:

- Handicapped persons must have opportunities to participate in or benefit from services which are equal to those that are provided to others. If preschool or vocational education services are available by law to children residing in a state, such services must be equally available to handicapped children.
- No handicapped child may be excluded from public education programs because of the nature or severity of a handicapping condition.
- Programs, including educational programs, *must* be made accessible. Structural changes in buildings are required only if alternative solutions are not possible — such as moving classes to ground floor locations where they can be attended by students who cannot manage stairs. Non-structural alterations must be made at once. Needed structural changes must be made by June 1980. Buildings begun after June 3, 1977 must be made physically accessible.
- Auxiliary aids, services and program modifications must be made so that handicapped individuals can participate in post-secondary education, such as vocational and college programs. For example, this can mean: a reader or tape recorder for a blind student, interpreter for a deaf student, course substitution, changes in length of time permitted to complete degree requirements.

What ages are covered?

Ages covered by P.L. 94-142 are 3-21 by 1980 — unless state law or practice does not provide for public school services for children 3-5 or 18-21.

YOU HAVE THE RIGHT TO DISAGREE

Both laws provide for a means of protest - if you feel that actions taken by a school are discriminatory, or not in your child's best interests, P. L. 94-142 sets down the rights of parents to call for a fair, impartial due process hearing if they are convinced that their child's evaluation, placement or services are inadequate or inappropriate. The law provides for an appeals system if hearings are not satisfactory.

- You must receive notice in writing before the school system takes (or recommends) any action that may change your child's school program.
- You have the right to give - or withhold - permission for your child to be: tested; placed in a specific school program to meet his needs.
- You have the right to see, examine, and obtain copies of all school records related to the identification, evaluation and placement of your child. You have the right to ask that misleading information be removed from your child's file.
- If you do not agree with the school's course of action at any point along the way, you have the right to request an impartial due process hearing.
- If you fail to win your case at the local level, you have the right to appeal.

More rights provided under 94-142:

- The parents must be invited to each IEP (Individual Education Plan) meeting. Parents may decide not to attend.
- If parents cannot be in attendance at the IEP meeting, the Local Education Agency (LEA) must provide alternate means of communication (phone, etc.)
- The LEA must provide parents with a copy of the IEP.
- Parents and Parent groups may provide input to annual program plans.
- Parent may request an explanation and interpretation of records. They may also have a representative review the record.

ALABAMA STATE LAW requires that the public schools serve all children (handicapped and non-handicapped) who have had their fifth birthday by October 1 of that school year. Young handicapped adults are eligible for public school programs until the school year when they have turned 21 by October 1. Some school districts have programs for children between the ages of 3 and 5 with specific disabilities (e.g., hearing-impaired). Parents are always advised to contact their local public school administration office to find out what programs are available.

MADISON AREA HIGH RISK PROJECT

Safety Tips for Infants and Toddlers

Burns

-Avoid scalds by always checking the temperature of the bath water and the temperature of foods and formula.
-Keep highchairs, playpens, and infants seats away from stoves, work areas, radiators, and furnaces. For safety, screens can be placed around radiators, floor furnaces, or stoves.
-Don't smoke while caring for the baby.
-Keep matches and cigarette butts out of children's reach.
-Keep coffee and other hot foods and hot pots and pans out of reach. Pot handles should be turned toward the back of the stove.
-Don't use dangling table cloths, these can be pulled and everything on them can crash on the baby and the floor.
-Avoid sunburn.
-Cover unused electrical outlets with safety caps or tape.
-Keep electrical cords out of reach.

Falls

-Never turn your back on a baby who is on a table, bed, or chair.
-Always keep crib sides up.
-Don't leave a baby on the floor, on a bed, or in the yard without watching him constantly.
-Fence all stairways - top and bottom.
-Remove tables or lamps that a baby could pull over onto himself.

Bath Safety

-Always check the temperature of the bath water prior to placing a child in the tub.
-Never leave a baby alone in the tub or wading pool. Babies can drown in a few inches of water. Toddlers can also turn on the faucet and scald themselves.
-Use mild soap and shampoo. Keep it out of the baby's eyes.
-Use cotton swabs only for cleaning the outside of the ear - do not poke them into the ear canal.

Crib and Playpen Safety

-Always keep crib sides up.
-Crib bars should be no more than $2\frac{3}{8}$ inches apart.

-Be sure mattress fits crib or carriage snugly so the baby can't slip between the mattress and the sides of crib or carriage.
-Don't tie toys to crib or playpen rails - babies can strangle on the string.

Toy Safety

- Select toys that are too large to swallow, too tough to break, with no sharp edges.
- Make sure that toys have been painted with non-toxic paint. Don't paint anything that a baby might chew on with paint that contains lead. This includes cribs, toys, furniture, and woodwork.
- Keep pins, buttons, coins, and plastic bags out of reach.
- Check all toys to make sure that they don't have removable objects such as eyes or buttons--these could be swallowed or choked on.
- Keep stuffed animal seams sewn, small children will put the stuffing in their ears and nose.

Poison Prevention

Poison Control Emergency Numbers:

1-800-292-6678

or

1-800-462-0800

- Select toys that are non-toxic.
- Never put anything that a baby can't eat or drink in a baby bottle, baby food jar, or baby dish--it could accidentally get fed to the baby.
- Keep all cans, bottles, spray cans, and boxes of all cleaners, detergents, pesticides, bleaches, liquor, cosmetics, and all medications out of reach.
- Don't leave ashtrays full of cigarette butts within a child's reach.
- Baby-proof all cupboards and drawers that can possibly be reached and sharp objects, breakable things, poisonous household products, plastic bags and foods that might cause choking, such as nuts or popcorn.
- If your house was built before 1940 and has any chipping paint or plaster, repair it completely and cover it with wallpaper or safe paint.
- Be especially careful when you or someone else in the family is sick. Medicines are likely to be out of their usual safe place.
- Never give medicine in the dark. Turn on the light and read the label - everytime.
- Keep medicine and household products separate. Also keep household products separate from food.
- Get one ounce of Ipecac Syrup and keep on the medicine shelf to treat poisoning.

Always check with your doctor, hospital, or poison control center before using Ipecac Syrup.

Car Safety

- Children 3 years old and younger must be restrained in a car seat - it is the law.
- The safest place for a car seat is in the middle of the back seat.
- Infants should ride in the backward - facing position at least until they can sit up on their own. The backward position allows the force of a sudden stop or crash to be absorbed safely across the infant's entire back area.
- Make sure that the car seat that you buy has been "dynamically tested".

-When purchasing a car seat check to make sure that the seat will fit well into your seat belt system in each car.

-It is important to find a seat that is convenient for you - one that you will use every time.

-Car seats for infants and toddlers may be obtained through the Red Cross. An infant car seat may be used for an infant weighing up to 20 pounds. A $25.00 deposit is required. $17.50 will be refunded upon return of the seat. A car seat for toddlers may be used up to the child's 4th birthday. A $35.00 deposit is required. $20.00 will be refunded upon return of the seat.

MADISON AREA HIGH RISK PROJECT

Developmental Fact Sheet I

(0-12 months)

This fact sheet demonstrates an average age of development for many basic skills. Each child is a unique human being who will grow and develop at his/her own rate.

Birth - 1 Month

- . . . eyes follow moving person
- . . . hands clenches on contact
- . . . quieted by familiar, friendly voice
- . . . makes small throaty noises
- . . . on stomach lifts head

1-3 Months

- . . . smiles responsively
- . . . anticipatory excitement
- . . . hands together at midline
- . . . talks back when talked to
- . . . on stomach, head up 45°

3-6 Months

- . . . holds up, looks at hand
- . . . reaches toward objects
- . . . puts object in mouth
- . . . turns to sound
- . . . regularly stops activity when name is called
- . . . shakes rattle
- . . . squeals
- . . . supported sitting, holds head erect and steady
- . . . on stomach, pushes up with straight arms
- . . . rolls over 1 way

6-9 Months

- . . . feeds self cookie
- . . . plays peek-a-boo
- . . . responds to image in mirror
- . . . picks up cup by handle
- . . . reaches for toy, both hands
- . . . bangs toy
- . . . stops or withdraws to "no"
- . . . recognizes words
- . . . imitates speech sounds
- . . . uses gestures for hi, bye-by
- . . . sits without support, 1 minute
- . . . stands, holding on

9-12 Months

- . . . eats semi-solid food
- . . . plays with ball
- . . . removes toy from under cup
- . . . puts object in cup
- . . . gestures to music or song
- . . . imitates cough or tongue click
- . . . say mama, dada
- . . . maintains standing position unsupported

Babies born at an earlier age than expected should be considered differently in terms of development. Premature babies may have some "catching up" to do. If a baby is born 2 months early and is 3 months old, his/her development may be at 1 month level. Subtract the number of months a child is born early,from his/her actual age.

MADISON AREA HIGH RISK PROJECT

Developmental Fact Sheet II

(12-36 months)

This Fact Sheet demonstrates an average age of development for many basic skills. Each child is a unique human being who will grow and develop at his/her own rate.

12-15 Months

. . . holds own cup, will drink
. . . motor initation with toy
. . . scribbles
. . . places peg in hole
. . . "help" turn pages in book
. . . gives toy on request
. . . makes wants known with gestures and voice
. . . crawls upstairs
. . . walks backwards

15-18 Months

. . . chews well
. . . uses spoon, little spilling
. . . builds tower of 2 cubes
. . . places 6 pegs in pegboard
. . . uses words to make wants known
. . . climbs
. . . walks upstairs holding rail
. . . gets in and out child-size chair
. . . heel-toe progression in walking.

18-24 Months

. . . defends own possessions
. . . turns pages of book singly
. . . turns knob
. . . points to 5 names body parts on doll
. . . initates some 2 and 3 word sentences.
. . . pulls toy while walking
. . . squats in play
. . . runs smoothly
. . . handedness is determined

24-30 Months

. . . parallel play
. . . indicates toilet needs
. . . washes and dries hands
. . . matches 1 shape
. . . matches 1 color
. . . carries out 2 related commands at once
. . . uses 2-3 word combinations
. . . sits on wheeled toy, propels forward

30-36 Months

. . . feeds self with spoon or fork
. . . pulls on shoes
. . . unbuttons easy buttons
. . . shares occasionally
. . . copies circle
. . . strings 4 beads
. . . identifies big and little objects
. . . relates recent experiences
. . . answers yes/no questions accurately
. . . uses alternate feet on stairs when going up

NICHCY
NATIONAL INFORMATION CENTER FOR HANDICAPPED CHILDREN AND YOUTH
P.O. BOX 1492 WASHINGTON, D.C. 20013

March, 1984

You Are Not Alone: For Parents When They Learn That Their Child Has a Handicap

By Patty McGill Smith

IF YOU HAVE RECENTLY LEARNED that your child is developmentally delayed or has a handicapping condition, which either is or is not completely defined, this message may be for you. It is written from the personal perspective of a parent who has shared this experience and all that goes with it.

When parents learn about any difficulty or problem in their child's development, this information comes as a tremendous blow. The day my child was diagnosed as having a handicap, I was devastated—and so confused that I recall little else about those first days other than the heartbreak. Another parent described this event as a "black sack" being pulled down over her head, blocking her ability to hear, see, and think in normal ways. Another parent described the trauma as "having a knife stuck" in her heart. Perhaps these descriptions seem a bit dramatic, yet it has been my experience that they may not sufficiently describe the many emotions that flood parents' minds and hearts when they receive any bad news about their child.

Many things can be done to help a parent through this period of trauma. That is what this paper is all about. In order to talk about some of the good things that can happen to alleviate the anxiety, let us first take a look at some of the reactions that occur.

Common Reactions

On learning that their child may have a handicap, most parents react in ways that have been shared by all parents before them who have also been faced with this disappointment and with this enormous challenge. One of the first reactions is that of *denial*—"this cannot be happening to me, to my child, to our family." Denial rapidly merges with *anger*, which may be directed toward the medical personnel who were involved in providing the information about the child's problem. Anger can also color communication between husband and wife or with grandparents or significant others in the family. Early on, it seems that the anger is so intense that it touches almost anyone, because it is triggered by feelings of *grief* and inexplicable *loss* that one does not know how to explain, nor how to deal with.

Fear is another immediate response. People often fear the unknown more than they fear the known. Having the complete diagnosis and future prospects can be easier than uncertainty. In either case, however, fear of the future is a common emotion: "What is going to happen to this child when he is five years old, when he is twelve, when he is twenty-one? What is going to happen to this child when I am gone?". Then other questions arise: "Will he ever learn? Will he ever go to college? Will he or she have the capability of loving and living and laughing and doing all the things that we had planned?".

Other unknowns also inspire fear. Parents fear that the child's condition will be the very worst that it possibly could be. Over the years, I have spoken with so many parents who said that their first thoughts were totally bleak. One expects the worst. Memories return of handicapped persons one has known. Sometimes there is guilt over some slight committed years before toward a handicapped person. There is also fear of society's rejection, fears about how brothers and sisters will be affected, questions as to whether there will be any more brothers and sisters in this family, and concerns about whether the husband or wife will love this child. These fears can almost immobilize some parents.

Then there is *guilt*—guilt and concern about whether the parents themselves have caused the problem: "Did I do something to cause this? Am I being punished for having done this? Did I take care of myself when I was pregnant? Did my wife take good enough care of herself when she was pregnant?". For myself, I remember thinking that surely my daughter had slipped from the bed when she was very young and hit her head, or that perhaps one of her brothers or sisters had inadvertantly let her drop and didn't tell me. Much self-reproach and remorse can stem from questioning the causes of the handicap.

Guilt feelings may also be manifested in spiritual and religious interpretations of blame and punishment. When they cry, "Why me?", or "Why my child?", many parents are also saying, "Why has God done this to me?". How often have we raised our eyes to heaven and asked: "What did I ever do to deserve this?". One young mother said, "I feel so guilty because all my life I had never had a hardship and now God has decided to give me a hardship."

Confusion also marks this traumatic period. As a result of not fully understanding what is happening and what will happen, confusion reveals itself in sleeplessness, inability to make decisions, and mental overload. In the midst of such a trauma, information can seem garbled and distorted. You hear new words that you never heard before, terms that describe something that you cannot understand. You want to find out what it is all about, yet it seems that you cannot make sense of all the information you are receiving. Often parents are just not on the same wavelength as the person who is trying to communicate with them about their child's handicap.

Powerlessness to change what is happening is very difficult to accept. You cannot change the fact that your child is handicapped, yet parents want to feel competent and capable of handling their own life situations. It is extremely hard to be forced to rely on the judgments, opinions, and recommendations of others. Compounding the problem is that these others are often strangers with whom no bond of trust has yet been established.

Disappointment that a child is not perfect poses a threat to many parents' egos and a challenge to their value system. This jolt to previous expectations can create reluctance to accept one's child as a valuable, developing person.

Rejection is another reaction that parents experience. Rejection can be directed toward the child or toward the medical personnel or toward other family members. One of the more serious forms of rejection, and not that uncommon, is a "death wish" for the child—a feeling that many parents report at their deepest points of depression.

During this period of time when so many different feelings can flood the mind and heart, there is no way to measure how intensely a parent may experience this constellation of emotions. Not all parents go through every one of these stages, but it is important for parents to identify with all of the potentially troublesome feelings that can arise so that they will know that *they are not alone*. There are many constructive actions that you can take immediately, and there are many sources of help, communication, and reassurance.

Seek the Assistance of Another Parent

There was a parent who helped me. Twenty-two hours after my own child's diagnosis, he made a statement that I have never forgotten: "You may not realize it today, but there may come a time in your life when you will find that having a daughter with a handicap is a blessing." I can remember being puzzled by these words, which were nonetheless an invaluable gift that lit the first light of hope for me. This parent spoke of hope for the future. He assured me that there would be programs, there would be progress, and there would be help of many kinds and from many sources. And he was the father of a retarded boy.

My first recommendation is to try to find another parent of a handicapped child, preferably one who has chosen to be a parent helper, and seek his or her assistance. All over the United States and over the world, there are Parent-Helping-Parent Programs. The National Information Center for Handicapped Children and Youth has listings of parent groups that will reach out and help you. If you cannot find your local parent organization, write to the National Information Center to get that local information.

Talk with Your Mate

Over the years, I have discovered that many parents don't communicate their feelings regarding the problems their children have. One spouse is often concerned about not being a source of strength for the other mate. The more couples can communicate at difficult times like these, the greater their collective strength.

If there are other children, talk with them, too. Be aware of their needs. If you are not emotionally capable of talking with your children or seeing to their emotional needs at this time, identify others within your family structure who can establish a special communicative bond with them. Talk with significant others in your life—your best friend, your own parents. For many people, the temptation to close up emotionally is great at this point, but it can be so beneficial to have reliable friends and relatives who can help to carry the emotional burden.

Rely on Positive Sources in Your Life

One positive source of strength and wisdom might be your minister, priest, or rabbi. Another might be a good friend or a counselor. Go to those who have been a strength before in your life. Find the new sources that you need now.

A very fine counselor once gave me a recipe for living through a crisis: "Each morning, when you arise, recognize your powerlessness over the situation at hand, turn this problem over to God, as you understand Him, and begin your day."

Whenever your feelings are painful, you must reach out and contact someone. Call or write or get into your car and contact a real person who will talk with you and share that pain. Pain divided is not nearly so hard to bear as is pain in isolation. Sometimes professional counseling is warranted; if you feel that this might help you, do not be reluctant to seek this avenue of assistance.

Take One Day at a Time

Fears of the future can immobilize one. Living with the reality of the day which is at hand is made more manageable if we throw out the "what if's" and "what then's" of the future. Good things continue to happen each day. Take time to "smell the roses."

Learn the Terminology

When you are introduced to new terminology, you should not be hesitant to ask what it means. Whenever someone uses a word that you don't understand, stop the conversation for a minute and ask the person to explain the meaning.

Seek Information

Some parents seek virtually "tons" of information; others are not so persistent. The important thing is that you request *accurate* information. You should not be afraid to ask questions, because asking questions will be your first step in beginning to understand more about your child. Learning how to formulate questions is an art that will make life a lot easier for you in the future. A good method is to write down your questions before entering appointments or meetings, and to write down further questions as you think of them during the meeting. Get written copies of all documentation from physicians, teachers, and therapists regarding your child. It is a good idea to buy a three-ring notebook in which to save all information that is given to you. In the future, there will be many uses for information that you have recorded and filed; keep it in a safe place. Again, remember always to ask for copies of evaluations, diagnostic reports, and progress reports.

Do Not Be Intimidated

Many parents feel inadequate in the presence of people from the medical or educational professions because of their credentials. Do not be intimidated by the educational backgrounds of these and other personnel who may be involved in treating or helping your child. You do not have to apologize for wanting to know what is occurring. Do not be concerned that you are being a bother or are asking too many questions. Remember, this is *your* child, and the situation has a profound effect on your life and on your child's future. Therefore, it is important that you learn as much as you can about your situation.

Do Not Be Afraid to Show Emotion

So many parents, especially dads, repress their emotions because they believe it to be a sign of weakness to let people know how badly they are feeling. The strongest fathers of handicapped children whom I know are not afraid to show their emotions. They understand that revealing feelings does not diminish one's strength.

Learn to Deal with Bitterness and Anger

Ultimately, bitterness and anger will hurt you a great deal more than they will affect those toward whom the anger is directed. It is very valuable to be able to recognize your anger and then let go of it. It is understandable that parents will be bitter and angry and disappointed to learn that their child has a serious problem. When you realize that these negative responses tend to hurt you and make you less effective with your child, you can decide to do something about them. Life is better when you are feeling positive. You will be better equipped to meet these new challenges when bitter feelings are no longer draining your energies and initiative.

Adopt a Grateful Attitude

It is hard to remain angry when one is grateful. Sometimes, when everything seems to be going wrong, it is difficult to find a cause for gratitude. However, in the scheme of things, if you look around and count your blessings, perhaps positive feelings can overtake the more negative ones.

Maintain a Positive Outlook

A positive attitude will be one of your genuinely valuable tools for dealing with problems. There is truly always a positive side to whatever is occurring. For example, when my child was found to be handicapped, one of the other things pointed out to me was that she was (and still is) a very healthy child. The fact that she has had no physical impairments has been a great blessing over the years; she has been the healthiest child I have raised.

Keep In Touch with Reality

To stay in touch with reality is to accept life the way it is. To stay in touch with reality is also to recognize that there are some-things that we can change and other things that we cannot change. The task for all of us is learning which things we can change and then to set about doing that.

Remember That Time Is on Your Side

Time heals many wounds. This does not mean that living with and raising a child who has problems will be easy, but it is fair to say that, as time passes, a great deal can be done to alleviate the problem. Therefore, time does help!

Find Programs for Your Child

Even for those living in isolated areas of our country, assistance is available to help you with whatever problems you are having. At the end of this paper, a person is listed who will help you get started in gaining the information and assistance you need. While finding programs for your handicapped child, keep in mind that programs are also available for the rest of your family, too.

Take Care of Yourself

In times of stress, each person reacts in his or her own way. A few universal recommendations may help: get sufficient rest; eat as well as you can; take time for yourself; reach out to others for emotional support.

Avoid Pity

Self-pity, the experience of pity from others, or pity for your child are actually disabling. Pity is not what is needed. Empathy, which is the ability to feel *with* another person, is the attitude to be encouraged.

Avoid Judgments

During this period, parents may become judgmental about the way people are reacting toward them or toward their child. Many people's reactions to serious problems are based on a lack of understanding, fear of knowing what to say, or fear of the unknown. Therefore, others may sometimes react inappropriately, but you need not use too much energy in being concerned over those who are not able to respond in ways that you might prefer.

Keep Daily Routines as Normal as Possible

My mother once told me, "When a problem arises and you don't know what to do, then do whatever it was that you were going to do anyway." Practicing this habit seems to produce some normalcy and consistency when life becomes hectic.

Remember That This Is Your Child

This person is your child, first and foremost. Granted, your child's development may be different from that of other children, but this does not make your child less valuable, less human, less important, or less in need of your love and parenting. Love and enjoy your child. The child comes first; the handicapping condition is second. If you can relax and take the positive steps just outlined, one at a time, you will do the best you can, your child will benefit, and you can look forward to the future with hope.

Recognize That You Are Not Alone

The feeling of isolation at the time of diagnosis is almost a universal feeling among parents. In this paper, there are many recommendations to help diminish those feelings of separateness and isolation. You can diminish these feelings by recognizing that they have been experienced by many, many others, that understanding and constructive help are available to you and your child, and that you are not alone.

Patty McGill Smith has recently moved to Washington from Omaha, Nebraska with her two youngest daughters, Marianne, age 17 and Jane, age 13. Jane, who was diagnosed at 14 months of age, has a mental handicap and epilepsy. She has been the source of inspiration for her mother's writing and her second career.

Patty's first career was at home raising seven children. The five older children are currently in five other cities of the mid-west. They are involved in careers in law, mental retardation, biology and two are in their first year of college.

The second career for Patty began as the staff coordinator of the Pilot Parents Program of the Greater Omaha Association of Retarded Citizens. This eventually became a four state center for Pilot Parents and a national resource for information about parent to parent programs.

In 1979 Patty moved to the Meyers Children's Rehabilitation Institute at the University of Nebraska Medical Center where she coordinated statewide services for parents, siblings, advocates, and professionals working with parents.

On January 16, 1984, she became Deputy Director of the National Information Center for Handicapped Children and Youth. Patty views this as a "wonderful opportunity" for a parent to serve as the link and liaison to parent organizations and groups nationwide. One of her major responsibilities will be to facilitate the exchange of as much current information and support among parents as possible. She invites parents everywhere to send information about the programs and the good things that are happening in helping parents where they live. Parents in need of assistance may write to:

Patty Smith, *Deputy Project Director*
National Information Center for Handicapped Children and Youth
1555 Wilson Boulevard, Suite 508, Rosslyn, Virginia 22209

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Handicapped Children and Youth
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Become Part of The National Exchange Network

With this newsletter, The National Information Center for Handicapped Children and Youth continues a two-way flow of information with you, the concerned people in communities across America. Let us know about the projects you are developing, the progress you are making, and the good things that are happening in services for the handicapped where you live. If we can hear from you, we can share your information with many others who will find it useful, and, of course, we will give full credit to the originators. Address your responses to: Toni Haas, Director, The National Information Center for Handicapped Children and Youth, 1555 North Wilson Boulevard, Suite 508, Rosslyn, Virginia 22209.

Madison Area
High Risk Project

July 22, 1985

Dear Parents:

I'm sorry this schedule and letter are getting to you later than usual. Last week had an unusual number of disruptions, including my being out on sick leave most of three days.

By now I believe that all of you have probably met Kim Cleveland, the HRP's new developmental specialist. Kim has found it most helpful for Karen to accompany her to the homes of our "old" families and to acquaint her with what parents and children have been working on in each case. Kim's real focus (which is actually the focus of the High Risk Project) is on teaching you, as parents, activities that you can do with your child. We all know that it is what you and your child do, day-in-and-day-out in the normal course of the day, that helps him/her develop. Kim has several different kinds of activity sheets, in addition to the Activity Charts we have been using, so you and she can find a style that works best for you and together you can be sure that you have the materials and understand the directions. This approach to the home visit might require more sitting-on-the-floor than in the past, but we think the benefits will be great for you and your child.

On the evaluation forms that we asked you to complete last April, one parent said he/she"would like to know where the guidelines for a child's development come from. Normal children excel in different areas. Why do they not expect this from special children?" To take the first part of the question first, the guidelines that we use to determine at what age a child should, ideally, acquire a skill and the order in which skills usually develop come from several sources. The HRP uses the Hawaii Early Learning Profile (three part fold-out charts) and the Portage Guide to Early Education Checklist to chart each child's skill acquisition on a regular basis. Both of these forms have about 600 items and give age ranges for the normal development of each skill. The age ranges were established after studying hundreds of children enrolled in federally funded demonstration projects, then were "field tested" and "normed" on thousands of children around the country. The age ranges are certainly not absolutes, even for children who are not developmentally delayed, but they are a fairly reliable benchmark and they do demonstrate the sequence in which related skills are usually developed. It is doubtful that there has ever been a child who has developed exactly according to any published chart. In most cases, gaining this or that small skill out of sequence has no real ramifications, as long as the "skipped over" skills develop soon. In some cases, though, this is not the case. Whole books have been written by educators and physicians explaining how children who never creep or crawl (but go right into walking) are at risk of having reading difficulties early in their school life. So, for the children in the HRP, it is the sequence, as much as (or more than) the age norms, of skill development that we particularly watch. This way we can be sure that you and we are working on new skills appropriate to your child's level of development.

As for why do we not expect "special" children to excel in different areas as "normal" children do, the fact that that question was asked tells me that we have not stressed enough the individualized aspect of the HRP's program. We do expect children enrolled in the HRP to have particularly strong areas, as well as others in which they are not as strong. Indeed, this is even more characteristic of developmentally delayed children than of others. In the HRP, the services each child receives are determined by his/her individual needs or strengths/weaknesses. Children whose speech or motor development is up to age level do not receive speech or occupational therapy. Children who are strong in all aspects of development except speech receive only speech therapy. In deciding what components of the HRP program a child will participate in, we are guided by those age norms mentioned earlier. The purpose of the HRP is to help children reach age norms in any area of development in which he/she is delayed, not to keep providing speech therapy until we turn a child with normal speech into an orator, but we rejoice when a child shows a particular strength, all the while continuing to work on areas where development is below age norms.

That's enough "Early Childhood Education in Theory and Practice" for one day. If whoever asked the above question, or anyone else, would like to talk about this further, please call.

Happy August!

Sincerely,

Susan

Susan J. Smith
Project Director

SJS/lj

HRP
Madison Area
High Risk Project

February 28, 1986

Dear Parents,

Three or four times a year the High Risk Project holds parent get-togethers on Sunday afternoons. Not only does this give you an extra opportunity to visit with other parents, but we also try to schedule a film or speaker of interest to many of you.

To start our 1986 "series", we invite you to the Opportunity Center, 513 Washington Street in Huntsville, on Sunday, March 16 at 2:00 p.m. We are showing a 25-minute videotape, "Gifts of Love," produced by the National Down's Syndrome Society. In the tape, parents speak of what it has meant to their families to have a child with Down's Syndrome. While it is focused on this particular group of families, the tape is of interest to all families whose children's development is not following "normal" patterns.

Since the tape is relatively short and we're an informal group, we're going to watch in one of the "baby-proofed" preschool classrooms at the Opportunity Center. Lap babies can sit in their favorite laps, while toddlers can play with toys on the carpet. We do hope you can come.

Sincerely,

Susan

Susan J. Smith
Project Director

P.O. Box 1063 • Huntsville, Alabama 35807
A Division of the Madison Co. ARC

HRP
Madison Area
High Risk Project

March 17, 1986

Dear Parents:

Happy Spring! It was something of a surprise to turn over a page on the calendar and start working on the April schedule. We hope that by the end of April we will be ready to move into our permanent room at First United Methodist Church. Remodelling and construction is still going on in that part of the building, but we will soon be able to use a room that we won't be sharing with any other groups. We'll let you know when this final move will take place.

Debbie Powell will be attending a conference on Early Intervention for the Handicapped in Birmingham on April 24-26. The conference is sponsored by several organizations there and includes topics of interest for professionals and parents. There is a fee of $45 if you register by April 9; $60 after that date. If you would be interested in going, let us know. We have extra copies of the brochure. Debbie would be happy to have you join her.

As most of you are aware, federal funding of the High Risk Project ends on September 30 of this year. We have a committee preparing to talk to state and local agencies, industries, etc., about helping to support the HRP. As part of this effort, we want to find out what you, as parents, see as valuable about the HRP. What are the most important or helpful parts of the program? Home visits? Speech? Occupational therapy and physical therapy? If we couldn't get quite enough money to continue the program as it is, what would you suggest we give up or cut back? If we got extra money, what should we add? Theresa Turner, an HRP parent on our funding committee, is going to try to call all of our families in late March and ask these questions and other related ones. Your responses are very important as we plan for the future, so we thought you might want to give these questions some thought before Theresa calls you.

We continue to welcome your ideas about possible places to look for money to continue the High Risk Project!

Sincerely,

Susan

Susan J. Smith
Project Director

SS:aj

P.O. Box 1063 • Huntsville, Alabama 35807
A Division of the Madison Co. ARC

Madison Area
High Risk Project

June 9, 1986

Dear Parents,

A mid-month news note is unusual in the HRP, but there are some special things going on that we want you to be aware of.

Dan and Jan Harris (parents of Matthew) have been talking with us for some time about organizing a parents' group for families in the HRP. They envision it as meeting fairly regularly and being a means for sharing information and support among parents. HRP staff members want to provide whatever help we can, but feel that a group organized of parents, by parents and for parents is best able to reach out to everyone. From time to time, many of you have asked about such a group to fill a need that the occasional HRP parents' meetings don't meet. We are delighted that Dan and Jan are going to get such a group started. I urge you to contact them at 859-2378 (in Huntsville) to join in the planning.

We have recently heard about legislation that has been introduced into the U.S. Senate to increase the number of programs available to handicapped and at risk children below school age. "The Education of the Handicapped Amendments of 1986" (known in the Senate as S. 2294) will face a stiff fight in Congress because it calls for $100 million for programs for very young children and will require all states to provide free education for all handicapped three- to five-year olds. This kind of requirement and support is going to be necessary before many states begin to offer such programs, even though they have been proven to be of great value to the children and to save money in the long run.

If you would like to have such a program available for your child, you need to write your congressman and senators and ask them to support this legislation. I've included copies of the letters I wrote so you can use them as a starting point. For the House of Representatives, I've included addresses for Ronnie Flippo (our congressman) and members of the House Subcommittee on Select Education. For the Senate, you'll find addresses for Heflin and Denton (Alabama's senators), Lowell Weicker (who introduced the legislation) and other members of the Senate Committee on Labor and Human Resources. Remember, if young children are going to receive their fair share of federal tax dollars, their parents and other advocates are going to have to fight for it. So let's do it!

Sincerely,

Susan

Susan J. Smith
Project Director

P.O. Box 1063 • Huntsville, Alabama 35807
A Division of the Madison Co. ARC

STAFF DEVELOPMENT

STAFF DEVELOPMENT

Staff development can really be looked at in two ways: (1) the organizing of a group of individuals in such a way that the purposes of the program are fulfilled, and (2) the providing of support and information to further the professional expertise of employees. The High Risk Project program objective pertaining to staff development reads

> 6. to provide for the continuing professional development of Project staff members through a combination of workshops, conferences and on-site visitations,

which addresses the second aspect of staff development. It is actually the first aspect that proved to be the greater challenge for the HRP in its first three years.

STAFFING PATTERN

When the HRP's grant proposal was written, the projected staffing pattern showed the Madison County Association for Retarded Citizens' preschool coordinator and executive director sharing all HRP administrative duties as part of the required local in-kind match of funds/time. Actual HRP employees were all direct service staff--a full-time developmental specialist, a physical therapist and a social worker, and a half-time registered nurse.

The developmental specialist provided most of the parent training and wrote most of the activity charts referred to in the "Services to Children" section of this report. The physical therapist's time was not fully utilized in providing therapy and parent training, so she was asked to coordinate the public relations aspect of the program. The social worker was expected to conduct intake interviews, coordinate services with other agencies and provide parent counseling, while the nurse concentrated on the health and nutrition of each child. Problems with this pattern developed soon:

(1) neither the developmental specialist, preschool coordinator nor executive director had clear responsibility or sufficient time to compile reports, etc., required under provisions of the grant;

(2) the physical therapist did not enjoy handling public relations for the program and did not feel that that was making good use of her professional skills and training;

(3) the social worker's ability to provide counseling to the parents was limited because the developmental specialist was most often in the families' homes and it was to her, not the social worker, that parents brought their problems and concerns; and

(4) the medical community did not feel it was appropriate for a program that professed to be developmental rather than medical to have a registered nurse on its staff.

Therefore, when the nurse and physical therapist both resigned for personal reasons, they were not replaced, but contracts were arranged, first with Huntsville Hospital, then with the Huntsville Rehabilitation Center to provide physical and occupational therapy on an hourly basis. An hourly contract was also arranged with the Center for Speech and Language Pathology to provide a speech-language pathologist to help parents with feeding problems and language development. The timeline on page 68 shows these and later staff changes.

At the beginning of Year Two, the position of HRP project director was created and responsibility for scheduling, evaluation, public relations and grant satisfaction was concentrated there. The social worker's position was reduced to three days, and later to two days, a week and was eliminated entirely midway through Year Two when the person holding that position moved out of the area. Her responsibilities were assumed mostly by the Project director, with the lending library and toy collection being coordinated by the developmental specialist.

When the social worker left the HRP, a second developmental specialist's position was created in response to the increase in the number of requests for service being received. A conscious effort was made to have developmental specialists with complementary, rather than similar, backgrounds so they could serve as resources to one another. Not only was the number of children the HRP could serve well increased, but the stability of the program was increased as well. On the two occasions since then when one developmental specialist's position was open, the remaining developmental specialist has been able to provide some continuity of services to families while the vacant position was being filled.

Contracting for physical, occupational and speech therapy on an hourly basis has also proven to be a wise decision, allowing expenses for such services to properly reflect the variation in the number of children being seen. A copy of the agreement between the HRP and the private physical therapist hired in Year Three is on page 69.

Because the Project director hired in mid-Year Two had both program evaluation and writing experience, the Association for Retarded Citizens personnel committee decided that the consultant positions of technical writer and evaluator provided for the Year Two budget would not need to be filled.

Employee job descriptions as they are at the end of Year Three are included in this report beginning on page 70.

PROFESSIONAL DEVELOPMENT

The High Risk Project's first developmental specialist was a recent college graduate with a background in working with orthopedically handicapped children. Her successor had a new B.S. degree in early childhood education for the handicapped, as did the third developmental specialist. The other two persons to fill this position (both working with developmental specialist #3) had backgrounds in working primarily with non-handicapped young children. Only one of the five was herself a parent.

The first developmental specialist became HRP director at the beginning of Year Two, but resigned two months later for personal reasons. The Project director for the last half of the three-year period had a master's degree in early childhood education, ten years experience administering programs for young children and was herself the parent of a school-age child with a learning disability.

The professional development needs of the various HRP staff members were very different, but basically they fell into two broad categories: (1) specific activities for children with specific disabilities, especially for those with severe impairments, and (2) approaches and techniques for working with parents.

Structuring schedules so that each developmental specialist attended each of her children's sessions with the speech, physical and occupational therapists not only facilitated carry-over of activities into the home, but served as professional development for the developmental specialists as well. The list below shows the wide range of other educational opportunities utilized by the various staff members.

Conference/Workshop	Date	Attending
HCEEP First Year Projects	10/83	Director
HCEEP Annual Conference	12/83	Director
Down's Syndrome Inservice	2/84	Dir,SocWkr,Nurse
CPR Certification	6/84	Dir,SocWkr,DevSpec
AL Conference on Child Care	10/84	Social Worker
HCEEP Annual Conference	12/84	Developmentl Spec
Confidentiality Inservice	2/85,11/85	Dir,SocWkr,DevSpec
Feeding Inservice	2/85	Developmentl Spec
PIP Workshop • • •	3/85,10/85,1/86	Developmentl Spec
Sensorimotor Integr. Symposium	7/85	Occupat.Therapist
AL Dept of Ed/DEC Conference •	8/85	Director
CEC/DEC National Conference •	10/85	Director
Managing the High Risk Infant •	2/86	Dir,DevSpec,Speech
Team Building Inservice	2/86	Dir,DevSpec
Alabama CEC Superconference •	2/86	Director
IEP Inservice	3/86	Dir,DevSpec
First Aid	4/86	Developmentl Spec
Augmentative Communication	4/86	Dir,DevSpec
Regional Confer. on Early • Intervention for the Handicap.	4/86	Developmentl Spec
Shunts	5/86	Director
Working With Families Whose Children Are Dying	7/86	Dir,DevSpec
Neuro-Devel. Treatment of CP	7/86	Dir,DevSpec,PT,OT,Sp
AL Dept of Ed/DEC Conference •	7/86	Dir,DevSpec

•indicates HRP brochures distributed

In addition to these formal professional development opportunities, observations were also arranged for appropriate

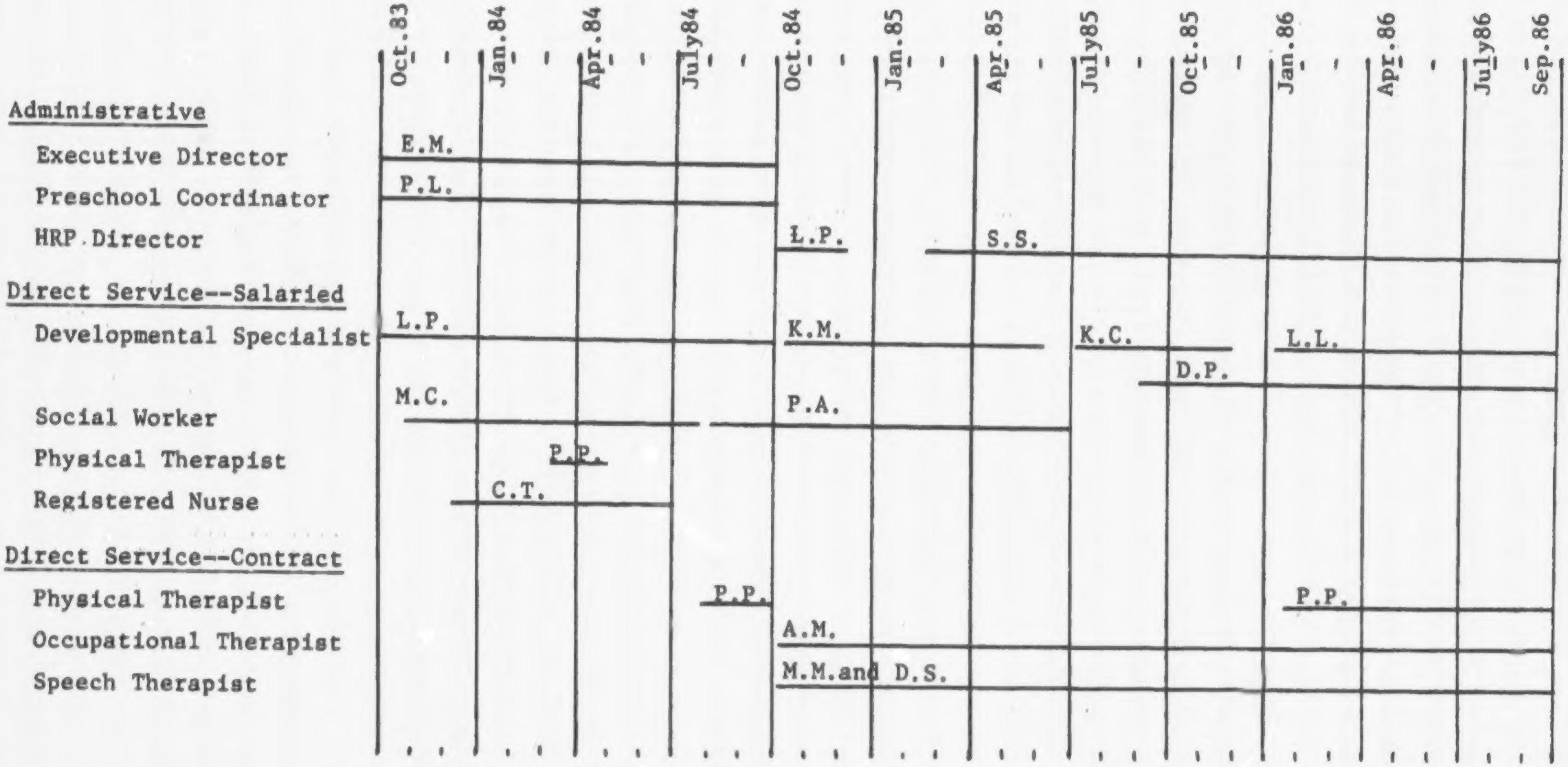
HRP staff members at

Follow-Thru Clinic	3/84, 8/84, 4/85
Center for the Developmentally Disabled	11/84, 1/86
Huntsville Hospital NICU	1/84, 8/84, 4/85, 4/86
Huntsville Achievement School	2/84, 4/86
Morgan County ARC	3/84
RISE Program, Tuscaloosa	3/84
U of AL CDLD, Genetics Ctr, NICU	4/84
Riverbend M.H. Center, Florence	3/85
CDLD, Jefferson County ARC	5/85
Councill School handicapped program	6/85
UCP Center, Huntsville	7/85,10/85
Regional Commun. Svc. coord's home visits	11/85,12/85
AL Institute for the Deaf and Blind	4/86
UCP Center, Gadsden	7/86

The Technical Assistance Development System (TADS) in Chapel Hill, North Carolina, also provided very needed and timely consultations in the areas of needs assessment, evaluation plans, demonstration and dissemination, and budgeting. When a desire to begin group classes grew out of the Comprehensive Program Review in April 1985, TADS arranged for a consultant from the Mental Health and Mental Retardation of Harris County (Houston), Texas, to visit the HRP for two days in July and for the project director and one developmental specialist to observe the Houston program in September. A large portion of the credit for the successful implementation of group classes goes to TADS for arranging these visits.

MADISON AREA HIGH RISK PROJECT STAFF

OCTOBER 1983 -- SEPTEMBER 1986



Initials indicate different individuals holding staff positions.

Madison Area
High Risk Project

LETTER OF AGREEMENT BETWEEN MADISON AREA HIGH RISK PROJECT AND [redacted] RPT

This agreement will constitute the necessary understanding for [redacted], RPT, to provide physical therapy and/or evaluations to the Opportunity Center, Madison Area High Risk Project (HRP) from November 4, 1985, to September 30, 1986.

1. [redacted] will provide physical therapy and/or evaluations of children enrolled in the HRP, as arranged by the HRP Director. The therapy/evaluations will take place either in the course of the Project's group classes or individually at the Opportunity Center. The HRP will provide all equipment necessary for such therapy/evaluations.

2. Reimbursement for such services will be $[redacted] per hour. [redacted] will complete the Opportunity Center staff time sheet and include on in the first names of the child(ren) for whom she performed the service. [redacted] will submit this time sheet to the HRP Director by the 25th of any month in which she is to be paid on the last day.

3. Written reports will be submitted within ten days after each evaluation. Time spent writing such reports will be documented on the time sheet and paid at the same rate.

4. Cancelled appointments will not be billed for, providing at least 45 minutes notice is given. No shows/uncancelled appointments will incur a charge equal to 15 minutes of therapy.

5. It is understood that the hours of service will be variable depending on the needs of the HRP and the ability of [redacted] to serve those needs.

6. This contract may be terminated by either party with 30 days written notice of the other party.

Susan J. Smith Dec. 18, 1985
Project Director date
Madison Area High Risk Project

[redacted]
[redacted] RPT date

Director date
Madison County Association for Retarded Citizens

Job Description

HIGH RISK PROJECT DIRECTOR

FUNCTION: The Project Director is responsible for administering the affairs of the Project to assure their compliance with the requirements of the funding agency and consistency with the philosophy and goals of the Project's grant proposal and the Madison County ARC.

DUTIES INCLUDE:

1. Assuming the responsibility for the total program, including:
   a. supervising the intervention/education program for children and parents;
   b. assisting the Executive Director in developing the annual operating budget;
   c. administering the annual operating budget;
   d. encouraging and providing for parent involvement;
   e. scheduling the most effective use of staff and resources; and
   f. planning for the future of the Project.
2. Conducting the intake of new families into the Project, including:
   a. making initial home visits;
   b. planning and directing placement committee meetings; and
   c. establishing and maintaining accurate records of all participants in the Project.
3. Serving as liaison between the Project and (a) TADS and (b) with the Executive Director, with the U.S. Department of Education.
4. Reporting frequently to the Executive Director on the status of the Project and,with him/her and the Advisory Board, conducting evaluations of the Project as required.
5. Maintaining relations with the Project's Advisory Board, including corresponding, scheduling and planning the agenda for meetings.
6. Providing referrals of families to appropriate social service providers as needed.
7. Representing the program to the community-at-large and encouraging the support and assistance of appropriate professional and community organizations and referral sources.
8. Developing and reviewing the required products (forms, policy statements, manuals, etc.) for the Project's continuing use and for demonstration and dissemination.
9. Maintaining qualified staff to assure the quality of services, including recruiting, selecting (with the ARC personnel committee), orienting, supporting, assigning responsibilities, evaluating (with the Executive Director) and providing for staff development.
10. Maintaining contracts with and coordinating services of PT, OT, speech therapist and other such individuals.
11. Recruiting, assigning and supervising volunteers working in the Project.
12. Participating in all IEP meetings and client staffings.
13. Participating in occasional home visits with the developmental specialist.

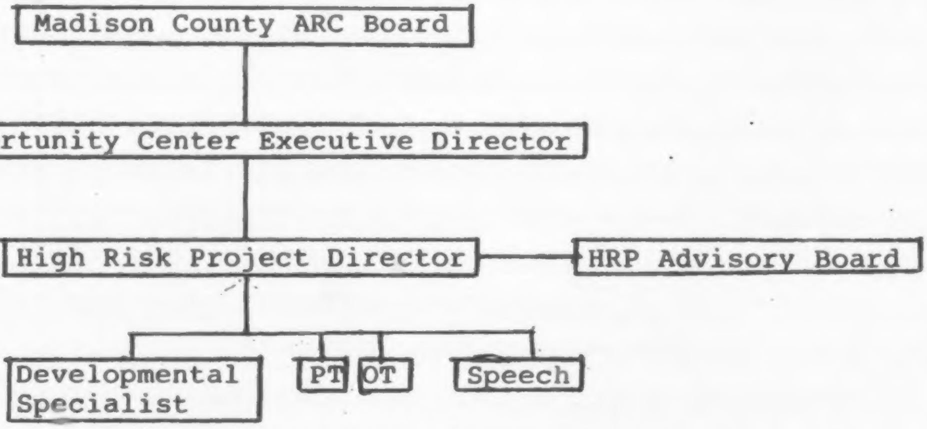
CONTINUED ON REVERSE.

14. Maintaining a current knowledge of the field of early childhood/special education.

15. Serving as an advocate for children and families in the community-at-large.

POSITION REQUIRES:

ORGANIZATIONAL CHART:


Madison County ARC Board
Opportunity Center Executive Director
High Risk Project Director
HRP Advisory Board
Developmental Specialist
PT
OT
Speech

Job Description

HIGH RISK PROJECT DEVELOPMENTAL SPECIALIST

FUNCTION: The Developmental Specialist is responsible for providing an intervention/education program for high-risk infants and toddlers and their parents in a manner consistent with accepted practices, the goals and philosophy of the Project's grant proposal and the Madison County ARC.

DUTIES INCLUDE:

1. Participating in each child's placement committee meeting.
2. Assessing the skill level in all developmental areas of each child enrolled in the program.
3. Participating in client staffings to determine range of services needed by each child and to facilitate coordination of services.
4. Preparing individual IEP's.
5. Coordinating and directing IEP meetings.
6. Coordinating various aspects of each child's programming, including:
   a. with input of client staffing, determining components of program in which child will participate;
   b. designing an appropriate program of skill-building activities; and
   c. training parents to carry out program.
7. Providing follow-up services for children released from program.
8. Maintaining toys and equipment in safe and sanitary condition.
9. Coordinating use of lending toy collection and library.
10. Arranging and supervising child care during Parent Support Group meetings.
11. Participating in staff meetings and inservice programs as scheduled.
12. Consulting with Executive Director and Project Director to evaluate Project.
13. Maintaining a current knowledge of the field of early childhood/special education.
14. Serving as an advocate for children and families in the community-at-large.

POSITION REQUIRES:

1. B.S. degree in early childhood education/special education.
2. One to two years experience working with infants and toddlers or the equivalent of one year in a practicum or student teaching .
3. Ability to relate sensitively to very young children and their parents.
4. Interest in upgrading professional qualifications by participation in staff development program.
5. Valid driver's license and daily access to a vehicle.
6. Health card.

ORGANIZATIONAL CHART ON REVERSE.

Job Description

HIGH RISK PROJECT SPEECH THERAPIST

FUNCTION: The Speech Therapist under contract to the Madison Area High Risk Project will provide an appropriate therapeutic program for children ages 0-3 in a manner consistent with the philosophy and goals of the Project's grant proposal and the Madison County ARC.

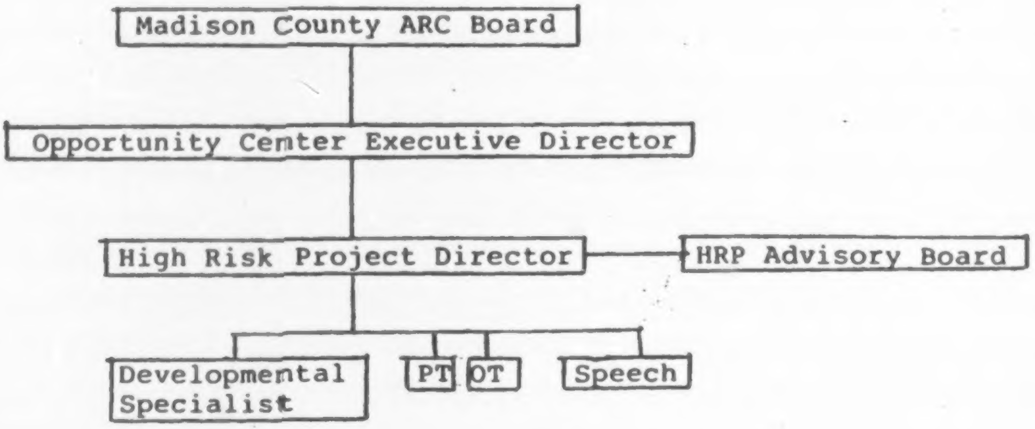
DUTIES INCLUDE:

1. Initial assessing of the speech and feeding status and development of each child referred to the therapist and quarterly reassessments as part of IEP process.
2. Submitting to the Project's Developmental Specialist, within ten days of each assessment or reassessment, a written report to include:
   a. a description of the observations;
   b. a list of goals and objectives to be achieved; and
   c. a personalized therapeutic home program of activities for parents to conduct between assessments.
3. Instructing and demonstrating to parents and/or Project staff specific activities described in written report and modifying activities as needed.
4. Participating in (1) monthly client staffings to determine the range of services needed by each child and (2) staff meetings as needed to facilitate the coordination of services and maintain effective communication among Project team members.

POSITION REQUIRES:

1. Professional certification and state licensure.
2. Ability to relate sensitively to very young children and their parents.
3. Health card.

ORGANIZATIONAL CHART:



Job Description

HIGH RISK PROJECT OCCUPATIONAL THERAPIST

FUNCTION: The Occupational Therapist under contract to the Madison Area High Risk Project will provide an appropriate therapeutic program for children ages 0-3 in a manner consistent with the philosophy and goals of the Project's grant proposal and the Madison County ARC.

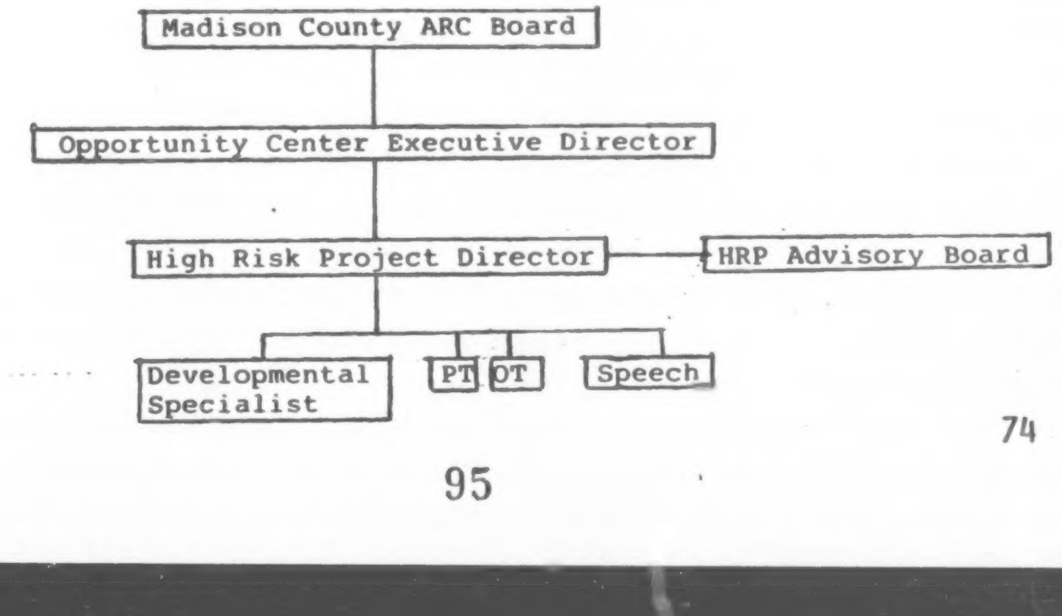
DUTIES INCLUDE:

1. Initial assessing of the gross and fine motor skills and development of each child referred to the therapist and periodic reassessments as changes and improvements are made.
2. Submitting to the Project's Developmental Specialist, within ten days of each assessment or reassessment, a written report to include:
    a. a description of clinical observations;
    b. a professional assessment of the child's strengths, weaknesses and resulting limitations;
    c. a list of goals and objectives to be achieved; and
    d. a personalized program of activity suggestions for parents to work on between assessments.
3. Instructing and demonstrating to parents and/or Project staff members specific activities described in the written report and modifying activities periodically as dictated by the child's progress.
4. Participating in:
    a. client staffings to determine the range of services needed by each child; and
    b. staff meetings as needed to facilitate the coordination of services and maintain effective communication among Project team members.

POSITION REQUIRES:

1. Professional registration.
2. Ability to relate sensitively to very young children and their parents
3. Health card.

ORGANIZATIONAL CHART:



COMMUNITY RELATIONS/DEMONSTRATION/DISSEMINATION

COMMUNITY RELATIONS/DEMONSTRATION/DISSEMINATION

The High Risk Project program objective which specifically speaks of community relations and outreach reads

> 7. to disseminate information about the High Risk Project and the needs of young children through the local media and distribution of Project materials to appropriate individuals and agencies.

This section will describe the efforts of Project staff members to inform the community about (1) the needs of families with young handicapped children and (2) the services provided by the HRP.

The first group targeted for informing about the HRP was the Huntsville medical community, since without their support and cooperation the Program would lose much of its effectiveness. The membership of the HRP Advisory Board has always included two pediatricians, one in private practice and one from the regional perinatal follow-thru clinic. Many of the initial referrals came from the Follow-Thru Clinic, then letters explaining the program were sent to the child's private physician if he or she had one. Progress reports are also written to physicians every six months when the child's IEP is updated. A sample letter is found on page 81. The HRP staff conducted two inservice training sessions for Huntsville Hospital NICU nurses in April 1984 and April 1986. In November 1985, 40 pediatricians at their weekly breakfast meeting viewed a newly developed slide presentation on the HRP. Following this presentation, there was an immediate increase in the number of referrals to the HRP by private pediatricians.

A real effort has been made to inform other potential referral agencies about Project services. Formal inservices were held for staff at the local mental health center and for Alabama Department of Pensions and Securities social workers and homemakers. Staff visits to other programs serving young handicapped children have always included sharing information about the HRP. Staff members from the Parent-Infant Program, the University of Alabama in Huntsville medical school, and child care center in an adjoining county have all observed HRP group classes. The HRP developmental specialist and physical therapist also visited this same child care center to instruct their staff in the handling of a child with spastic cerebral palsy.

Other opportunities to disseminate information among professional groups and students include presentations to the Madison County Opportunity Center staff (March 1984), Madison County Health and Social Services Committee (March 1984), University of Alabama in Huntsville undergraduate education class (January 1985), Alabama A & M University undergraduate sociology class (November 1985) and State Crippled Children Service (September 1986).

The response of the local media to efforts to publicize the HRP was generally positive, resulting in newspaper articles about the program in April 1984 and November 1985 and local television news segments in November and December 1983 and February, July, August and September 1986. One radio interview was conducted with the HRP director in October 1984 and notices of the parent support meetings were submitted to 13 radio stations for broadcast as public service announcements.

Various community events provided other opportunities to disseminate information about the HRP. Displays were arranged and brochures distributed at the local health council's Health Fair (September 1984), the Jaycees' Northeast Alabama State Fair (September 1984), Huntsville Volunteer Days (September 1985) and Humana Hospital's Baby Fair (March 1986).

The Project director has also been an active member of the local Council on Adolescent Pregnancy and Parenthood, a newly organized group whose members come from many community agencies.

With the help of the local United Way staff, a special slide-tape presentation was created in 1986 to be used in the search for funding to continue the HRP beyond its federal grant period. This program has been shown to the Huntsville City Council and employees of McDonnell Douglas, Boeing Military Airplane Company, and the Huntsville Kiwanis Club. Two hundred fifty NASA employees also viewed the presentation during tours of the Opportunity Center arranged by United Way during the fall of 1986.

An important aspect of the HRP's community relations has been the composition of its Advisory Board. During quarterly meetings the board has provided guidance to the Project staff, and individual members, because of their particular expertise, have served as resources for the staff. Equally important, however, was the ability of many board members to use their positions in the community to advocate for young handicapped children and their families. Members of the HRP Advisory Board include

Huntsville City Schools special education coordinator
Madison County Schools psychometrist
Two public schools special education teachers
Alabama A & M Univ. special education professor
Two pediatricians
Speech pathologist
Madison County Mental Retardation Svcs. Coordinator
MH/MR Regional Community Services Coordinator
State Crippled Children Service representative
Huntsville Hospital social worker
Public relations specialist
Three parents
Former HRP director

PRODUCTS AND MATERIALS

The HRP's grant proposal included plans to produce several written manuals and packets, some of which have been completed as planned, some consolidated in their final form and others abandoned completely. With the amount of staff turnover that the Project had experienced by the middle of Year Two, it became obvious that some aspects of the original proposal could not be met. Therefore, the decision was made to concentrate on developing a service delivery system that served children and families well and to complete only those products which were a direct outgrowth of that effort. Appropriate U.S. Department of Education personnel concurred in that decision.

The HRP brochure, completed in September 1984, was designed to be used as the program grew and changed. An easily updated fact sheet inserted in the brochure describes specific program components and enrollment information. Copies of the brochure and fact sheet are found on pages 30-31 of this report. Brochures have been distributed at the nine conferences indicated on page 66, as well as to all job applicants, at all fairs listed, and to all who attended any inservice or other presentation by an HRP staff member. Brochures were also distributed through area social service agencies, the regional perinatal follow-thru clinic and organizations such as the Mothers of Handicapped Children Club.

As discussed in the "Services to Children" section, early plans for the development of "activity charts" were abandoned because of the lack of curriculum-writing experience among the staff and the inability to standardize the curriculum on the small number of children enrolled in the HRP. Energy previously devoted to completing the charts was focused on cross-referencing established curricula as listed on page 12. While the formal Curriculum Utilization Manual referred to in the proposal has not been compiled, the cross-referencing list is available for dissemination.

Once the HRP staff realized that most of the children served by the Project were of less than two years' chronological age and of even lower developmental age, plans to develop a guide for children's trips to the library, police station and other community sites were dropped as being unrelated to the other services of the HRP.

The Project Policies and Procedures Manual completed at the end of the federal grant period reflects the program as it was in September 1986. It is anticipated that the manual will be changed as changes occur in the program.

Since staff development needs depend on the experiences and training that staff members bring to their positions, a staff training manual was not written, but efforts were made to combine attendance at regional workshops, HRP inservice training and professional literature to meet the needs of individual staff members.

Development of the two slide presentations--one designed for education, one for fundraising--provides the HRP with tools for continued dissemination to the community of information about the needs of families with young handicapped children and the importance of early intervention programs.

H R P
Madison Area
High Risk Project

September 5, 1985

Dr. [redacted]
[redacted] Street
Huntsville, AL 35801

RE: [redacted]

Dear Dr. [redacted]

The Madison Area High Risk Project, funded through a federal model development grant, has been working with families of handicapped and "at risk" infants and toddlers since January 1984. Your patient [redacted] has been enrolled in the Project since late July of this year.

The High Risk Project's services are designed to complement the medical services you and other physicians provide for [redacted] Our developmental specialist/home teacher keeps track of [redacted]'s developing cognitive, self-help, social and gross and fine motor skills. During bi-weekly visits in his home, we show his parents play activities to encourage the development of new skills. We loan specific toys from our toy collection and try to serve as a supportive listener when his parents have concerns about non-medical aspects of his development. We have a policy of refusing to answer questions we may be asked about medical issues--rashes, how much weight a child should be gaining, etc.--and suggest that such questions be asked of you or another physician.

In addition to the developmental specialist/home teacher, [redacted] sees our Project's speech and language therapist monthly. While he is too young for us to be concerned about any articulation errors, the speech therapist works with his parents to teach them how to encourage good language development by talking to him all day about what they are doing and responding to his vocalizations, using different pitches and volumes. As he gets older, [redacted] may well go on a bi-weekly speech schedule.

[redacted] is also being seen by our occupational therapist monthly, not so much for direct therapy as for assessing gross and fine motor development and teaching his parents how to help him develop new skills in those areas. Our current goals for him are to develop better head control and to decrease the hypertonia in his lower extremities.

Eligibility for the High Risk Project is open to all children less than 36 months of age who have a diagnosed handicapping condition or who are at risk of being delayed in any area of development. The enrollment process is begun by the parents' completing an application and your completing a simple medical referral form. Our placement committee, including Dr. [redacted] [redacted], then decides the appropriateness of the program for each child.

I have taken the liberty of enclosing copies of both of those forms, as well as a couple of copies of our program brochure, in case you have

P.O. Box [illegible] • Huntsville, Alabama [illegible]

another patient whose family you think might benefit from enrollment in our program. [redacted]'s parents gave us permission to share this information with you, so I am sure that they would be willing to discuss the program, from their perspective, either with you or with other parents. I also trust that you will contact me at the Opportunity Center (539-2266) if you have any questions or concerns about either the Project in general or [redacted]'s specific program.

We are enjoying working with [redacted] and his family and would be delighted to get to know any of your other patients for whom you think our program might be appropriate.

Sincerely,

Susan J. Smith

Susan J. Smith
Project Director

copy: Mr. and Mrs. [redacted]

PROGRAM EVALUATION

PROGRAM EVALUATION

Any organization, particularly a young one, that provides services to people needs to engage in frequent, almost constant, evaluation of its effectiveness. For the High Risk Project, a thorough program evaluation needed to answer two questions:

(1) Did the program achieve its stated objectives? and

(2) Were the families enrolled in the program satisfied with the services provided?

The HRP program objectives have been discussed in each of the foregoing sections, so evaluation of the extent to which each was achieved will be kept brief.

SERVICES TO CHILDREN

1. to provide an early intervention program in North Alabama for 30-40 high risk infants ages 0-36 months with all levels of handicapping conditions.

2. to provide an effective means of assessing children's progress by establishing, evaluating and updating every three to six months Individual Education Plans (IEPs) for each child participating in the Project.

5. to provide a smooth transition for children between the Project and public schools or other agencies by providing resource and training assistance to these organizations.

Program objective one stated that the HRP intended to serve 30-40 high risk infants and toddlers with all levels of handicapping conditions. In fact, some 60 children were served during the three years of federal funding, with a maximum of 34 children being enrolled at one time. The fact that some children "outgrew" their need for an early intervention program while others eventually were referred to more intensive programs indicates that enrolled children had varying degrees of disability or delay.

The second HRP program objective states that each enrolled child should have an Individual Education Plan and that such IEPs should be updated every three to six months. The format of the Project's IEP changed during Year Two so they could be continually updated, if needed, within the six month period for which each was written. Only four children did not remain enrolled in the Project long enough to receive a complete initial IEP.

Transitions for children between the HRP and the public schools or other agencies is the topic of the fifth program objective. The HRP's experience has been that, when children left the Project for other special education programs, the receiving agency usually requested copies of the child's developmental records (released only with parents' permission) and other personal information, but actual training was only provided to one child care center that was providing respite care for a child with cerebral palsy.

SERVICES TO PARENTS

3. to provide training for parents to assist and support them in teaching their child needed skills.

4. to provide four informative parent meetings each year.

Since guiding and supporting parents in their efforts to help their children learn new skills is the main focus of the HRP, the program objective which addresses this issue could be considered the heart of the Project. Such guidance and support was definitely provided. Its effectiveness is the subject of the "Parents' Evaluation of the HRP" portion of this section.

If providing assistance and support to parents brought the greatest satisfaction to HRP staff members, attempts to provide informative parent meetings probably was the greatest source of frustration. In Years One and Two, this objective was met, though the meetings were often not well-attended. In Year Three other approaches to facilitating parent interaction and providing information were used more frequently than organized meetings and seemed to produce equally acceptable results.

STAFF DEVELOPMENT

6. to provide for the continuing professional development of Project staff members through a combination of workshops, conferences and on-site visitations.

Although frequent staff turnover brought personnal with different professional development needs, most HRP staff members felt supported in their attempts to broaden their professional backgrounds. A total of 535 hours of staff development was provided during the first three years of the HRP.

DEMONSTRATION/DISSEMINATION

7. to disseminate information about the High Risk Project and the needs of young children through the local media and distribution of Project materials to appropriate individuals and agencies.

While any program administrator would probably like to increase the amount of media coverage his/her program receives, HRP staff members were generally satisfied with the Project's television and newspaper coverage. While articles and appearances never brought a great immediate increase in the number of inquiries about the program, the benefits of the publicity were very evident in the long run. Not only was the community made aware of the HRP, but tne needs of families with handicapped and developmentally delayed children were given increased visibility. It was not uncommon after a presentation to a community group for the Project director to be approached by a member of the audience who said, "I've had a hard time relating to what my relative/neighbor/friend is going through with her premature baby. Now I think I understand better."

The distribution of Project materials to this point has been limited primarily to the HRP brochure, but with the completion of this report and the Policies and Procedures Manual, it is anticipated that the dissemination of materials will increase. A list has been kept of all requests for information that could not be met at the time received so materials could be sent when they were completed.

STAFF EVALUATIONS

The Madison County Association for Retarded Citizens and the High Risk Project utilized several staff evaluation forms in an attempt to find one that best reflected an employees' ability to meet the expectations of the Project. The evaluation form on page 95, completed on a staff member in Year Two, is the one being used as of this writing.

An important element of information at several stages in the Project's life has been the distribution of each staff member's time among the various aspects of her position. A copy of the developmental specialist's time accountability form and its companion sheet are on pages 96 and 97 of this report. The Project director completed a similar form with administrative tasks listed for accounting. The forms were completed for a three-week period in August-September 1985 and for three weeks again in August-September 1986. A comparison of the two periods (see below) shows an appropriate shift in the use of the developmental specialists' time as the program matured and they had been in their positions for a longer period of time. It should be noted that August-September 1985 was a period of great program expansion and that during August-September 1986 IEPs were being prepared or updated for all children enrolled in the HRP.

Developmental Specialist

Task	Percentage Of Time Spent On Task	
	1985	1986
Direct service to parents	*	*
Direct service to children	8%	28%
Preparation for services to children	44%	38%
Travel to children's homes	10%	21%
Staff development	14%	--
Communication with other agencies	1%	1%
Administrative	5%	2%
Other	18%	10%

*Developmental specialists reported difficulty distinguishing between direct services to parents and direct services to children.

A comparison of the Project director's time accounting for the same two periods reflects the fact that in August-September 1985 she was involved in expanding the program and supporting two relatively new staff members, whereas August-September 1986 saw the focus changed to seeking continuation funding and satisfying the requirements of the federal grant.

Project Director

Task	Percentage Of Time Spent On Task	
	1985	1986
Services to parents	6%	11%
Services to children	28%	4%
Travel	4%	6%
Staff development	3%	--
Demonstration/dissemination	9%	6%
Communication with other agencies	13%	17%
Program evaluation	--	4%
Grant satisfaction/funding	10%	22%
Other administrative	17%	24%
Other	10%	6%

PARENTS' EVALUATIONS OF HRP

The real effectiveness of the High Risk Project is measured not by statistics, but by how much assistance and support parents felt that they received from Project staff members. The Project's original proposal included plans for staff members to evaluate parent-child interactions and parent teaching techniques. However, after working with families for about eighteen months, staff members realized that the parent-child interactions that they observed during home visits did not always reflect accurately the parent-child relationship when no visitor was in the home. Consequently, the staff decided not to try to quantify as a measure of the Project's effectiveness changes in family interactions while the family was enrolled in the HRP. Instead, parent perceptions of and satisfaction with HRP services was considered to be the important aspect of program evaluation.

At four different times during the HRP's first three years, parents were formally asked their opinion of the program staff and services. In addition to their responses to these surveys, many parents offered suggestions or constructive criticism in face-to-face discussions or in phone conversations. Project staff members always tried to respect such suggestions and the Project director tried to discuss criticisms with parents when that seemed appropriate. Several of the minor changes made in the structure of the HRP services developed from parents' suggestions.

In October 1984 a "Parent Project Assessment Questionnaire" was mailed to the ten families enrolled in the HRP. Responses from the seven families returning the form were very favorable, with the greatest approval being shown for project staff and somewhat less approval of or understanding of activity charts and the IEP process. This information was used in planning future IEPs and in modifying the format of the activity charts before they were discontinued. A copy of the "Parent Project Assessment Questionnaire" is included on pages 98-99, with numbers indicating the number of families giving each response and longhand answers copied verbatim.

In April 1985 parents again were asked for their opinions or comments about various aspects of the HRP. A copy of the instructions and compiled responses to questions are found on pages 100 through 103. The "Parent Evaluation of Project Services" showed again that parents considered the HRP staff members to be the major strength of the program. From their participation in the Project, parents said they had both learned new skills to help their child develop and changed their attitude toward and perceptions of him/her. They were most positive about home visits and recognized the fact that their children generally respond best in familiar surroundings. Suggestions for changes or improvement in HRP services included providing more written materials, avoiding afternoon appointments, scheduling make-up sessions, and discontinuing use of the activity charts.

On his/her evaluation form, one parent posed a question about where IEP guidelines for a child's development originate, so that question was responded to in the next parent newsletter. The establishment of morning group classes and the moving of the lending library to the classroom responded to two other issues of parents' concern. As parents became more aware of the number of families enrolled in the HRP, they realized that rescheduling missed appointments was usually logistically impossible. While written ideas and activity suggestions are often left with parents following a home visit, the requirement that they record how many times the activity was tried each day was soon discontinued.

In the Spring of 1986, as the search for funding to continue the HRP was hitting high gear, the funding committee and Project staff realized the need for a more recent survey of parents' impressions of program services. Particularly important were the parents' views of the relative value of home visits and therapy sessions in case the amount of funding received was not sufficient to support the full range of services. The HRP parent member of the funding committee volunteered to make a telephone survey of parents to obtain their views on these and other topics. The funding committee recognized the fact that several Project families do not have home telephones and others might be reluctant to confide in someone they did not know, but it was decided that the potential for good results justified the effort. The list of questions drawn up for the telephone interviews is on page 104, along with shortened versions of the responses received. Because of unexpected constraints on the availability of the parent making the calls, only five of the 30 enrolled families were contacted, so no broad conclusions were drawn from the responses, except that they tended to reinforce the results of the two previous evaluations.

In August 1986, just prior to the end of the Department of Education grant, a third written evaluation form was sent to HRP families. Responses to this evaluation indicated the same high degree of approval of staff-parent interaction. Issues that had drawn some criticism in the past--particularly scheduling and the IEP process--were seen as more satisfactory. Home visits were still generally considered the most helpful aspect of the program. The fact that speech therapy is considered the least helpful by five parents may indicate that Project staff have not adequately discussed pre-speech language development with parents.

Because it was felt that parents of children who were no longer enrolled in the Project might have a different perspective on the HRP services they had received, a specially designed form was sent to 15 previously enrolled parents. However, responses families. Parents did generally feel that HRP staff had been helpful in finding another appropriate program for the child when he/she was ready to leave the HRP.

Copies of both evaluation forms, with indications of the number of families giving each response, begin on page 105, followed by a compilation of answers given to the open-ended questions.

STAFF MEMBERS' EVALUATIONS OF HRP

A formal staff evaluation of the High Risk Project's services was not actually conducted, but part of the preparation for the writing of this report included discussions of what staff members felt the HRP had done most successfully and what their greatest frustrations had been. Without exception, staff members felt that the support and training provided to parents was the strongest aspect of the HRP. The flexibility and individualization of services to families is considered a very positive aspect of the program. The HRP staff agrees with the parents that the provision of services in the home is a major factor in the success of the program and helps staff members see the families as families, rather than as clients. The Project's collection of toys and adaptive equipment available for loaning is also considered a strong asset, particularly by the physical therapist.

Various staff members evaluated highly the communication between staff members about the individual children and the ability of the staff to support one another in attempts to help families and to improve the HRP. One developmental specialist listed as a positive factor the personal satisfaction that she receives from working with these families, but at the same time mentioned the frequent emotional stress brought on by the job.

Several aspects of the program that staff members would like to change--more time for the therapists to see each child in group class, the separation of the HRP office and group classroom in two buildings one-half mile apart, the long drives to the homes of some of the children, and the lack of a parent support group--are basically unchangeable for either financial or logistical reasons.

Several suggestions for changes in group classes are probably workable and will be tried soon--a more isolated area for the speech-language pathologist's use, an opportunity for a feeding evaluation for each child, and an occasional therapy session for each child outside the group class time. In these discussions, as it often has before, a difference in the various staff members' orientations toward group classes surfaced, with the developmental specialist regarding this as parent training time and the therapists wanting more time for direct therapy.

Several staff members had suggestions regarding staff meetings, from a desire for more professional development to a request for more time to thoroughly discuss each child's needs at least monthly.

Other suggestions for the program included the development of a plan to get more HRP children into auxiliary services and more opportunities for staff to observe other programs.

Overall, the HRP staff is very proud of the services that the Project offers to the families of young handicapped and developmentally delayed children.

EMPLOYEE PERFORMANCE EVALUATION

Name: [redacted] Job Title: Developmental Specialist

Program Area: High Risk Project

Areas of Responsibility:

1. Services to parents and children--
   [redacted] has good rapport with the parents we serve. She is empathetic, yet able to discuss problems in a matter-of-fact manner. She shows concern for all of the children as individuals, remembering and respecting their preferences and dislikes. She says that, with the demands of family, church, and job, she often feels emotionally drained and unable to be as supportive of parents as she would like to be. I have noticed her "low" times in the office, but seen her rally for interactions with parents.
2. Planning, recordkeeping--
   [redacted] has redesigned forms and streamlined procedures to make the IEP and recordkeeping processes easier to manage. She is always well organized, working from lists in planning home visits, meeting deadlines, etc. She says she wants to spend more preparation time before making home visits - something she can arrange within her own schedule.
3. Coordination with other staff--
   [redacted] works well personally and professionally with other staff members, sharing information and helping them meet IEP and other deadlines. She has the respect of all those she works with.
4. Other related duties--
   [redacted] sanitizes toys and performs other routine tasks on her own initiative. She also has suggested topics on which inservice is needed.

Comments: As Project Director, I have promised to continue providing [redacted] with opportunities to "recharge" herself (e.g. sharing written materials, arranging observations of other professionals), and as much as is possible, to avoid scheduling late afternoon appointments, when she is least energetic. SJS

Performance Rating: Excellent
Recommend for permanent status.

[redacted]
Employee

Dates

Susan J. Smith
Project Director

Oct. 14, 1985

Executive Director
Acting

Oct. 15, 1985

TIME ACCOUNTABILITY FORM -- DEVELOPMENTAL SPECIALIST

Name ____________________

Date ____________________

	MODULE / TIME		8:00				9:00				10:00				11:00				12:00				1:00				2:00				3:00				4:00			
			1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
Services to Parents	Planning, Research *	S																																				
		Hr																																				
	Correspondence, Telephone *	S																																				
		Hr																																				
	Materials Development *	S																																				
		Hr																																				
	Direct Svc. *	S																																				
		Hr																																				
	Other *	S																																				
		Hr																																				
Services to Children	Assess, Evaluate, Plan	S																																				
		Hr																																				
	RecordKeeping, Charts	S																																				
		Hr																																				
	Materials Development	S																																				
		Hr																																				
	Co-ord with other staff *	S																																				
		Hr																																				
	Direct svc.	S																																				
		Hr																																				
	Other *	S																																				
		Hr																																				
	Staff Development *	S																																				
		Hr																																				
	interaction w/ other progs, agencies *	S																																				
		Hr																																				
Prog. Evaluation	Parent Svcs. *	S																																				
		Hr																																				
	Child Svcs. *	S																																				
		Hr																																				
	Accountability *	S																																				
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	Other *	S																																				
		Hr																																				
	Equipment Management *	S																																				
		Hr																																				
	Staff meetings *	S																																				
		Hr																																				
	Other administrative *	S																																				
		Hr																																				
	Non-work *	S																																				
		Hr																																				
	Travel *	S																																				
		Hr																																				
		S																																				
		Hr																																				
	TOTAL																																					

* also on administrative form

TIME ACCOUNTABILITY FORM -- CATEGORIES

Services to Parents

--Planning, Research--reading to prepare for Parent Support Group, etc.

--Correspondence, Telephone--any conversations with parents outside regular programming

--Materials Development--for Parent Support Group, Parent Library, etc.

--Direct Service--Parent Support Group

--Other

Services to Children

--Assess, Evaluate, Plan--developing IEPs and activities, etc.

--Recordkeeping, Charts--completing HELP charts, home visit reports, etc.

--Materials Development--writing activity charts, etc.

--Co-ordination with Other Staff--staffings, arranging reports, etc.

--Direct Service--home or group sessions

--Other

Staff Development--participation in workshops, reading of professional literature not directly related to an individual child or group

Interaction with Other Programs, Agencies--Crippled Children's, Follow-Thr

Program Evaluation

--Parent Services

--Child Services

--Accountability--completing of this form

--Other

Equipment Management--includes purchasing trips, sanitizing, etc.

Staff Meetings--Project planning, etc. (does not include staffings)

Other Administrative

Non-Work--personal phone calls, etc.

Travel--to children's homes, group classes, etc.

Parent Project Assessment

Questionnaire

		N	S	A	NA
Staff					
(a)	Does staff appear knowledgable in areas of child development, "at-risk" conditions and parent/child interactions?			7	
(b)	Have staff members given you information on your child's development and/or handicapping condition when requested?			7	
(c)	Are staff members available for consultation, support, and home visits when needed?			7	
(d)	Do staff members talk in language you can understand and assist you in understanding terms discussed by other professionals?			7	
(e)	Are staff members prompt for appointments?			7	
(f)	Do you feel free to discuss problems, accomplishments, fears, and others with staff members?			7	
(g)	Do staff members listen while you speak?			7	
rocedures					
(a)	Do you understand the procedures taken to develop your child's IEP including assessments, evaluation summary, IEP meeting and IEP documentation?		3	3	
(b)	Do you have a clear understanding for the need of activity charts?		1	6	
(c)	Are activity charts helpful at home? with activities?		3	4	
(d)	Are activity charts clearly stated in language you understand, easy to follow, and neat in appearance?		3	4	
(e)	Do staff members demonstrate clearly both child activities and teaching methods?		1	6	
Services					
a)	Do staff members refer you to supportive agencies when needed?			4	3
b)	Do you feel the project has been helpful to you and your child?		1	6	
c)	Do you feel your child's needs have been addressed?		1	6	
d)	Do you feel the home program component has been helpful (working with parent and child in home)?		1	6	
e)	Do you feel physical therapy has been helpful?		1	6	
f)	Do you feel speech therapy has been helpful?		1	4	2
g)	Have Parent-to-Parent Support Group Meetings been helpful and/or interesting to you?		1		5
h)	Have gatherings for all project families been beneficial?		1	2	4

Please add any comments you may have about the quality of the project nd any recommendations .

N - Never S - Sometimes A - Always NA - Not Applicable

RP - 209 10/84

PARENT COMMENTS WRITTEN ON
PARENT PROJECT ASSESSMENT QUESTIONNAIRE
OCTOBER 1984

Wonderful people.

Staff have been very supportive.

We love each and every one, present and past, of the staff members and are well pleased with them.

I do appreciate the help and support you have given to us.

I feel that if it hadn't been for the program that C. wouldn't of gotten as far as he has and I would not of known what to do about alot of situations that we have been faced with.

This project is especially helpful to our family needs. I would like to thank you for including us in this project.

Program is very informative.

Some activities charts are in language that is hard to remember; the explanation given by the teacher is not usually enough to remind me for two weeks.

I do feel that family gathering will help because it will give us time to meet and maybe help others or ourselfs. And also to let everyonelse know that their not the only family with this problem.

Madison Area
High Risk Project
P.O. Box [illegible]
Huntsville, Alabama 35807

PARENT EVALUATION OF PROJECT SERVICES

Purpose: To discover parents' reactions to the Project's services for themselves and their children. To be used by Project staff to improve services.

Instructions: Please give us your honest opinion about the Project and its services. We encourage both parents (where appropriate) to respond, using different colored inks or pen/pencil so we can sort out responses separately. Please write N/A after items that don't apply to your family; leave an item blank if you don't care to make any comment about that aspect of the Project. Return the completed evaluation in the enclosed envelope by ________________.

As is the practice with all incoming Project mail, envelopes are opened and discarded by the Opportunity Center's administrative assistant, so all identifying postmarks will be removed before reaching Project staff. All responses will be treated anonymously and held in strict confidence, used only to help Project staff continually upgrade services.

THANK YOU FOR YOUR HELP IN THIS EVALUATION PROCESS!

COMPILATION OF RESPONSES TO PARENT EVALUATION OF PROJECT SERVICES--APRIL 1985

Do you feel that you have gained any new skills/knowledge/attitudes from your participation in the Project? If so, please describe.

--I feel that I have gained more knowledge of my child that he is even more advanced than we even realized.

--Yes. I know better how to work with my son to help him improve his motor skills.

--I think I have learned to accept my child for what he is right now. Simply because he was born less than "normal and healthy" doesn't mean he cannot be loved and enjoyed as other children are. I am proud of his accomplishments and try hard not to compare my children with each other. Each child develops at a different rate and I make an effort not to think that because one isn't walking when his brother was, that it is bad.

--Yes. skills--we have learned to use play as a tool for teaching; knowledge--same as skills, also we are more aware of the problems not only with our child but also others in the community; attitudes--we have a more understanding attitude toward the teaching of all handicapped children.

--Yes, I feel my family and friends have learned from me and my child being involved with this program. And I have changed a lot of person's attitudes toward Down Syndrome children.

--The project has been the only source for planned activities to be done at home. Not only have they provided activities, but are very compassionate, kind people who genuinely care for the welfare of my child and family. Without their support, I really don't know what I would have done.

What do you see as the major strengths of the High Risk Project?

--Staff--very caring and knowledgeable. Very supportive.

--The caring teachers on their home visits I feel like they a sincere in their actions and their teaching of my child and I.

--All the personnel, particularly [redacted], show that they are truly interested in the child. They are very good at giving encouragement to the parents, which helps us work better with the child.

--The dedication the teachers have in developing and eductaing delayed or handicap children is superb. Keep up the good work.

--Resources--the ability to obtain help from speech therapist, physical therapists, Dr. [redacted], etc. All of the children have such different problems, yet with all of this program's resources you are able to find help not only for the Downs child but also for the child with a less severe problem.

--The therapists are very cooperative and friendly, and take time to explain the different exercises.

--The poeple themselves. The are very helpful in all areas.

What do you see as the major weaknesses of the High Risk Project?

--I think the project does the best it can do to help all people accepted into the Project.

--Too much paperwork--but I can understand that since it's federally funded.

--Staff turnover has been a problem, however, it seems to be improving. It is important for both parent and child to be comfortable with staff members and that has been difficult in the past with the numerous changes.

--None.

--To encourage communication between families of special children. Encourage visits to the center, I feel this would help understand the future needs of our children.

--None.

What do you think the Project could do to be more useful/helpful to you?

--Have hand booklets with age and how to help get your child up to that level.

--Have make-up sessions when either I or the therapists aren't able to attend.

--I think the Project is working pretty much full potential for us. Hopefully, at the end of the three year program, they will be able to suggest the next step for each of the children in the project.

--I can not see any area where improvement is needed.

--Thank you. I think the project has helped my family more than I could have asked.

--Provide more information on projects or other groups in the area. Provide articles or reading material on special children.

--They go out of their way to be helpful. They do as much as limits will allow.

Please give us your comments on:

Home sessions with developmental specialist:

--Excellent.

--Sessions are well planned and always go well depending on my child's mood.

--[redacted] is great! We look forward to each session.

--I think the home sessions are of most importance, because the child is more likely to cooperate and do the task ask of them in their own environment.

--We are very pleased with home visits. [redacted] is able to observe the child in his normal setting and give us advice and suggestions on things we might do just in our normal day-to-day routine.

--[redacted]'s very helpful. She works well with my son. She's good at providing suggestions for activities.

--They have helped me to learn more about my son.

Services provided by social worker:

--They are very understanding to problems.

--[redacted]'s nice, but I can't see that she really does a lot.

--[redacted] is very supportive. Sometimes just letting a parent talk and [redacted] listending is helpful, and [redacted] is a good listener. The reading list she sent out listing what the library has for us was appreciated.

--She frees the developmental specialist from other tasks so she is able to spend more time with the children.

--[redacted] has done an excellent job in scheduling of appointments to our convenience and also occupying our older child on home visits.

--Would like more information on development and programs in the area.

--Excellent.

Speech therapy:

--Excellent.

--[redacted] is very good and very concerned about the children.

--[redacted] has done an excellent job with our baby and we are very grateful.

--We have a problem with the time speech is scheduled. 2:45 is naptime and the child is not at his best. Also school age children are coming home at this time and arrangements for them have to be made. [redacted] runs late quite often, but she seems interested in the children and seems to work well with them.

--N/A.

--I really like [redacted]. She's given lots of helpful suggestions for activities for my son.

--Very friendly and caring to the children.

Physical/occupational therapy:

--N/A.

--She seems to really know what she's doing.

--N/A. We have only been one time.

--Maybe should be scheduled more often.

--Very good suggestions in body strengthing exercises.

--N/A.

--Excellent.

Communication/relationship with Project staff:

--Excellent.

--No complaints.

--Excellent.

--Excellent.

--Very good. The staff seems interested in not only the child in the program, but also other children and parents. The monthly calendars P[redacted] sends out with our appointments are very helpful.

--Very good.

--They try to help you in all areas.

What Project expects of you (activity charts, transportation, etc.):

--They expect us to work with the child but to me the projects they give us are more play then work.

--I don't feel the activity charts are really necessary. A list of activities to be done would be better.

--The activity charts are a pain to keep up with, but it gives both the parents and staff some idea what progress the child is making.

--I wish I could do more.

--I have a hard time keeping up with charts.

--The project cannot do everything. It's only fair that parents keep up charts and provide their own transportation.

Parent Support Group:

--Have not attended but interested nevertheless.

--Parents need to be encouraged to talk more often.

--We have only attended one meeting which was not exactly what we had expected. However, we are looking forward to hearing Dr. F[redacted] and I feel as parents come to know each other the meetings will become somewhat less awkward and very interesting.

--Very helpful! Meetings are very interesting. I like the informal atmosphere.

--I have not attended any of the parent support group sessions.

Your child's individual education plan (IEP):

--It helps to know what goals to aim for.

--This is a way parents can tell that their child is making progress. I see things much clearer when they are on paper rather than someone just telling me.

--Very fair evaluation and realistic goals.

--Very good.

--Would like to know where the guidelines for a childs development come from. Normal children excell in different areas why do they not expect this from special children.

--Excellent.

Any other pertinent topic:

--I am very grateful that my child was accepted into the project. The improvement has been tremendous--I cannot thank the staff enough for all the work, concern and love that they have shown.

--To be honest, we had given a lot of thought into dropping out of the program late last year. There had been so many staff changes, there was no one really in charge. We wondered if it really was worth the effort. However, things have improved greatly with the new year and we are glad we stayed. This program not only involves your child, it involves you and your entire family. I feel like we are giving our high risk

Madison Area
High Risk Project

PARENT TELEPHONE SURVEY
SPRING 1986

Questions--short; Answers--broad

1. Has the High Risk Project helped you? Yes (from all 5 respondents) very pleased; health problems have kept him at home--HRP has helped; support for the family

2. Do you think the home visits are important? Yes (from all 5 respondents)

   one-on-one; gets to ask questions; very important!(from 2 respondents)

   a. Is your child's behavior different at home from group classes?

   yes; sometimes; yes, does better at home; more comfortable

   b. If travelling to the home was no longer possible, would you be able to participate in the HRP regularly?

   Yes (from 3 respondents); Yes, because HRP volunteer provides transportation to group class; would try to--depends on child's health

3. Are the group sessions beneficial to you?

   Yes (from 3 respondents); No (from 1); (fifth child doesn't attend)

   a. Do you like the chance to visit with other parents?

   Yes (from 2); No; Not a chance to visit

   b. Do you benefit from seeing the therapists?
   Yes (from 3); No, not enough time spent with child, no one-on-one teaching

4. Have you made use of the lending library toys and books?

   Yes; Sometimes; At first; Not yet; Hasn't had a chance yet

5. If we came up short of money to run the whole program, what do you think the HRP could do without and not hurt what you get out of it?

   Lending library; home visits; home visits; reconstruct group classes--maybe one long visit per month instead of ten minutes per week; keep home visits! couldn't do without anything; benefits from the whole program; occupational and physical therapy overlapping?

6. What else could the HRP do to help you?
   very helpful; directory of parents; support group (from 3); nothing; parent meeting on Down's syndrome;

7. Is there anything else you especially like or would like to see changed?

   excellent job; would like to see continue; likes the program; no problems; spend more time with therapist; meet parents at group classes

Parent's name ____________________ Phone number ____________________

Madison Area
High Risk Project
P.O. Box 1063
Huntsville, Alabama 35807

CURRENTLY ENROLLED FAMILIES

Compiled Responses

31 forms sent; 20 returned

September 1986

The High Risk Project is required to do an evaluation at the end of its three-year federal grant. For us to do this, we need to know how you feel about the services you and your child have received. Most of the questions just need for you to circle your answer. (You can make comments too, if you wish.) A few questions at the end need for you to give us your ideas in your own words. Please complete the form and return to us in the enclosed envelope by September 1. Thanks for helping us with this part of our report.

Susan Smith

1. How much does the HRP staff seem to know about your child's condition?

Nothing	A little	A medium amount	Lots
	1	4	15

2. Has the HRP taught you anything about your child and his/her condition?

Nothing	A little	A medium amount	Lots	I already knew everything
	2	7	11	

3. Has the HRP given you ideas you can use with your child?

None	A few	Some	Lots	I never needed any
		1	19	

4. Have the developmental specialists and therapists shown you how to do activities?

Never	Rarely	Sometimes	Lots	I never needed it
		2	17	

5. Do the developmental specialists and therapists explain things so you can understand?

No, they use too many technical words	I can usually understand	I can always understand
	9	11

6. Do you feel like you can discuss things that bother you with HRP staff?

Not at all	I can discuss anything	I can discuss some things	I haven't needed to discuss anything
	15	4	1

7. Do you feel that your child's IEP accurately shows what he/she is able to do?

Not very accurate	Fairly accurate	Very accurate	I'm not sure
1	4	11	

8. Do you feel like you are a partner in planning your child's IEP?

No, I'm not very involved	I'm only involved a little	Yes, I'm involved
	1	16

9. Have you borrowed toys or books from the HRP?

Not at all	Sometimes	Many times
8	7	4

10. Did the HRP work out a convenient program schedule for you?

No, it's not convenient	It's fairly convenient	Yes, it's very convenient
	3	17

11. How do you feel about the frequency of HRP services?

Not often enough	About right	Too often
2	18	

12. Do you feel the HRP has been helpful to your child?

Not at all	A little	Some	Very helpful
		3	16

13. Do you feel the HRP has helped you know more about how to help your child?

Not at all	A little	Some	Very helpful
		2	18

14. Overall, how pleased are you with the services the HRP has provided you and your child?

Not pleased	A little pleased	Fairly pleased	Very pleased
		3	16

15. Would you recommend the HRP to other parents?

Definitely not	Maybe	Definitely yes
	1	19

16. Which HRP service has been most helpful to you?

Home visits	Speech therapy	Physical/occupational therapy	
8	4	6	"all"--3

17. Which HRP service has been least helpful to you?

Home visits	Speech therapy	Physical/occupational therapy
1	5	3

18. In what area do you feel your child has gained the most while in the HRP?

Gross motor	8	Fine motor	5	Cognitive	1
Language	3	Self-help	4	Social	4

19. In what area do you feel your child has gained the least while in the HRP?

Gross motor		Fine motor	4	Cognitive	
Language	4	Self-help	5	Social	2

20. What have you liked most about the HRP?

21. What have you like least about the HRP?

22. What could the HRP do to be more helpful to you?

Is this information correct? Enrolled in HRP ______________________

Participated in: ____Home visits _____Speech _____Physical/occupational

THANKS AGAIN!

Madison Area
High Risk Project
P.O. Box 1063
Huntsville, Alabama 35807

PREVIOUSLY ENROLLED FAMILIES

Compiled Responses

15 forms sent; 7 returned

September 1986

The High Risk Project is required to do an evaluation at the end of its three-year federal grant. For us to do this, we need to know how you feel about the services you and your child received while you were enrolled in the HRP. Most of the questions just need for you to circle your answer. (You can make comments, too, if you wish.) A few questions at the end need for you to give us your ideas in your own words. Please complete the form and return to us in the enclosed envelope by September 1. Thanks for helping us with this part of our report.

Susan Smith

1. Did the HRP teach you anything about your child and his/her condition?

Nothing	A little	A medium amount	Lots	I already knew everything
	2	3	1	1

2. Did the HRP give you ideas you could use with your child?

None	A few	Some	Lots	I never needed any
		2	5	

3. Did you feel like you were a partner in planning your child's program and services?

No, I wasn't very involved	I was only involved a little	Yes, I was involved
		7

4. Did you borrow toys or books from the HRP?

Not at all	Sometimes	Many times
1	5	1

5. How did you feel about the frequency of HRP services?

Not often enough	About right	Too often
3	4	

6. Did you feel the HRP was helpful to your child?

Not at all	A little	Some	Very helpful
		3	4

7. Overall, how pleased are you with the services the HRP provided you and your child?

Not pleased	A little pleased	Fairly pleased	Very pleased
		2	5

8. Would you recommend the HRP to other parents?

Definitely not	Maybe	Definitely yes
	2	5

9. Did the HRP staff help you find another program when you were ready to leave the HRP program?

No	Yes	Didn't need help	Didn't need another program
2	4	1	

10. Which HRP service was most helpful to you?

Home visits	Speech therapy	Physical/occupational therapy
5	1	1

11. Which HRP service was least helpful to you?

Home visits	Speech therapy	Physical/occupational therapy
1		3

"all were helpful"--2

12. In what area do you feel your child gained the most while in the HRP?

Gross motor	2	Fine motor	1	Cognitive	2
Language	1	Self-help	1	Social	1

13. In what area do you feel your child gained the least while in the HRP?

Gross motor	1	Fine motor		Cognitive	
Language	2	Self-help	1	Social	2

14. What did you like most about the HRP?

15. What did you like least about the HRP?

16. What could the HRP have done to be more helpful to you?

Is this information correct? Enrolled in HRP ______________

Participated in: _____Home visits _____Speech _____Physical/occupational

THANKS AGAIN!

COMPILED RESPONSES TO OPEN-ENDED QUESTIONS--PARENT EVALUATION FORM 9/1/86

20. WHAT HAVE YOU LIKED MOST ABOUT THE HRP?

Currently enrolled parents--

--the concern of the staff for each child

--I appreciate most about the HRP the morale support, the information they are able to provide me with. The therapy and exercize they provide for my son.

--New ideal's for helping T. Willingness to listen.

--The therapists have all been very helpful and cooperative.

--You see other children with same problems or worst. It has taught me to teach my child.

--The concern that is shown for D.

--Support for parent. [redacted] [redacted] has been most open and supportive. I don't feel placated or judged--the way most physician's handle mothers.

--Home visits, speech therapy, physical/occupational therapy. Staff seem to know about his condition and given ideas to help him.

--Everyone really seems to care about S. and his progress; they have all been very helpful.

--Friendly, relaxed method of working with the family.

--The chance to meet and be with parents with similar children; liked the speech therapists especially.

--The staff has been so helpful to us about our son. All phases or services offered by HRP are very helpful. We were guided in the right direction for our child.

--The workers are always ready to answer any questions and give advise for my child.

--I like the home visits. The meeting is also benificial. My son enjoys the other children. My son is catching up to his age of two.

--They're true concern and they're support for helping our daughter.

--Home visits the therapist is great.

--HRP was very knowledgeable about development of my child.

--Everyone has been so helpful and nice and very supportive. The program has taught me so much I didn't even begin to know about helping M. M. has a twin so I thought the physical things would come much easier for her, but I was very wrong. This program has taught me so much for M.,and had I have known some things before, her twin would probably have done things sooner herself. It has really opened my eyes to many things.

--The HRP has given me so many helpful ideas as far as therapy for H. And also they have taken a lot of time to show me how to incorporate play into everyday therapy.

--S. has enjoyed the home visits and seems to learn well in her home. I like the small classes and feel we get more attention with less distraction.

Previously enrolled parents--

--The transportation they provided for us. The therapists at work with my child. Giving me new ideas.

--Being there to help when I needed support.

--Very concerned, helpful staff. Always available to answer questions and offer support.

--Home visits were very helpful, speech and physical therapy was also helpful but I feel that home visits were the best because my child was around his own surroundings.

--Their willingness to work with parent and child and to be flexible about the program according to the individual's specific needs.

--One on one contact with teacher.

--The friendly staff members and their genuine concern for all the children.

21. WHAT HAVE YOU LIKED LEAST ABOUT THE HRP?

Currently enrolled parents--

--I wish the group classes could be a little longer, but I feel the therapist really make excellent use of the time and equipment they have.

--I feel like the group classes should be alittle bit longer but the quality of the time spent is great.

--I feel when you have a child with developemental problems any parent would be willing to spend all of their spare time helping and educating their child. Personally I

could spend all day with someone showing me knew ways and ideas of helping my child, which I know is impossible. I really don't have anything I don't like. If anything, maybe just more group class time with each therapist.
--Toys that were available for lending.
--Nothing--everyone has been great.
--Nothing, they're great.
--My son just started the program, the staff is trying to get to know him. If I had known about it sooner, I would have brought him in.
--I don't really feel that some conditions of some children such as my child (spina bifida) should have the same therapy as a child with a different condition. Each child is different with different needs.
--No dislikes.
--Not organized with other support groups in the area.
--Nothing.
--Thinking that they won't get the necessary funding to continue the program they way it is now.
--Nothing.
--Not to be ungrateful or inconsiderate, but group sessions with unattended "normal" children running loose. I can understand the rationale, but you did ask and I hope I haven't offended anyone.
--Not being able to meet other parents with children like D. (does not attend group)
--Not enough parent get togethers.
--The distance in traveling to therapy.
--So far away.
--The thing I like least is probably the location of the HRP.
--Home visits.

Previously enrolled parents--
--Group classes never acomplished a lot.
--The many personnel changes--it was difficult for both parent and child to switch teachers so often.
--Well because the employee turned over too often it did not let the child get used to one person.
--Not enough funds to do more for children.
--Decrease in the one-on-one time.
-- Not enough time for therapy at the center.

--There was nothing that I didn't like about HRP. I just wish other kids could benefit from this program.

22. WHAT COULD THE HRP DO/HAVE DONE TO BE MORE HELPFUL TO YOU?
Currently enrolled parents--
--Spend more time with each child.
--Not sure. They seem to be doing a good job.
--Having more one-on-one communication with the therapist during the time M.'s not seeing her.
--Nothing. Everything that [redacted] does while she is visiting D. has been more than helpful enough. Thank you [redacted].
--Recommend books and or articles on L.'s developmental problems. Sometimes questions don't come to mind at times with professionals. Not all questions have answers.
--To have more time with him.
--I can't think of anything right now but I'll let you know if I do!
--Continued service.
--Be more active in providing organization for parents support groups.
--Very pleased with the present HRP.
--Understand that even Spina Bifida babies are different and even have different capabilities.

--The staff seems to be doing such a good job. They have already been helpful.
--Have more home visits.
--I guess more home visits.
--Keep us posted on how much our child has developed.
--Maybe hold group support classes. Each child is different in his/her own way regardless of their problems. But lots of times ideas from parents with hands on experience of a slow child sometimes enlightens you to knew ideas or ways to stimulate your child.
--Be closer to our home. The benefits we have received make the trip worth it.
(No response from 3 forms.)

Previously enrolled parents--
--I would have liked to have had more time to talk to the therapists on a one-on-one basis about N.
--The HRP have done a lot my child. I don't think they could have been more helpful. Just only if they had more time to spend with the children privately.
--All was appreciated.
--Offered more services to children. However, due to lack of funds that was not possible. They did a wonderful job with available funds.
--Nothing.
--I feel our need were met in every way.
(No response on one form.)